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**Critical Care Diaries: a qualitative study exploring  
the experiences and perspectives of patients,  
family members and nurses.**

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# Abstract

This thesis describes a qualitative study exploring the use of critical care diaries from the experiences and perspectives of patients, family members and nurses in a Scottish Intensive Care Unit (ICU). Diaries are currently used in some ICUs across Europe, the UK, Australia and other countries to help patients come to terms with the experience of critical illness. Started in the ICU, the diary is written at the bedside by nurses and family members providing an account of what happened when the patient was in ICU. Following discharge, the diary is handed over to the patient for them to read and refer to during their recovery. Therefore, the diary is used by different people, at different times and in different ways throughout the critical illness journey. However, until recently, research has mainly focused on the diary being read by the patient after ICU as an aid to recovery with little known about family members and nurses despite them being the main authors during the time in ICU. This doctoral research was designed to explore critical care diaries from multiple perspectives and experiences to gain a greater understanding of the different ways in which diaries can be used. Furthermore, it is the first known research study in this area to have been undertaken in NHS Scotland where the use of diaries remains a relatively new practice.

The theoretical perspective of Symbolic Interactionism helped to inform the development and design of the research study. A focused ethnographic approach was taken to explore the use of critical care diaries from the different groups identified, during and after a stay in ICU. The setting was an Adult ICU in Scotland where diaries were being used as part of a follow up service for patients and family members after ICU. Data were collected from February 2013 to June 2014. Semi-structured interviews were the main method of data collection. A purposive sampling strategy was adopted to recruit participants in triads with a related patient, family member and nurse involved in their care during the time in ICU. This is a novel and unique approach to research in this area. Four complete triads and two incomplete triads were recruited giving a total of sixteen interviews with four patients, six family members and six nurses. Interviews were supplemented with a small number of formal observations of nurses carrying out diary related activities

(n=9) and field notes from time spent at the site. Transcribed interview data were analysed using a thematic approach, uncovering five main themes: (1) Information; (2) Communication; (3) Emotion; (4) Person Centered and (5) Gender. The concept of ‘Stories as joint actions’ developed by the sociologist Ken Plummer in 1995 was used as a framework to discuss and explain the findings.

Diaries were found to support information sharing and facilitate communication interactions between nurses, family members and patients in the ICU as well as promoting and demonstrating a person centered approach to care. Emotional support was experienced by family members from writing in and reading the diary during the time in ICU whereas patients experienced emotional support from reading diary entries after the time in ICU. However emotional effort was associated with reading and writing in the diary during and after the time in ICU for patients, family members and nurses. Male family members were found to be less likely to write in the diary compared to female family members. Factors such as gender and literacy appeared to influence diary use however this requires further investigation. A new conceptual model ‘Critical Care Diaries as Joint Actions’ was created to address the complex nature of experiences with critical care diaries.

Exploring the use of diaries from multiple perspectives and experiences has provided valuable insight into the different ways in which diaries are used during and after the time in ICU demonstrating that although the diary is primarily written for the patient, family members, nurses and patients use the diary in different ways to support their needs and others needs throughout the experience of critical illness.

## Lay summary

Critical Care Diaries are currently being used in some Intensive Care Units (ICUs) throughout the world to help patients come to terms with the experience of a critical illness. Patients often cannot remember what happened when they were in ICU as a result of their illness and the medication and treatments they receive. Therefore, the diary is written to the patient while they are critically ill in ICU, providing a story of what happened. Written by the bedside nurse and visiting family members the diary is different to any other document used in ICU as it does not contain clinical information normally recorded in medical notes. Furthermore, when patients are discharged from ICU the diary is handed over to them for them to keep and refer to during their recovery.

The research was designed to gain an understanding of the experiences and perspectives of patients, family members and nurses with Critical Care Diaries in an Intensive Care Unit.

The research was conducted in an ICU in NHS Scotland which was already using diaries for patients. Patients, family members and nurses were invited for an interview about their experiences with the diary. Sixteen interviews were completed with four patients, six family members and six nurses. Additionally, the researcher kept notes detailing the time spent in the ICU conducting the research and observed nurses carrying out different activities with diaries, for example when the diary was handed over to patients after discharge from ICU.

Diaries were found to support information sharing and communication between nurses, family members and patients in the ICU as well as promoting and demonstrating care that was focused on the patient and their family. Emotional support was experienced by family members from writing in and reading the diary during the time in ICU whereas patients experienced emotional support from reading diary entries after the time in ICU. However emotional effort was associated with reading and writing in the diary during and after the time in ICU for patients, family members and nurses. Male family members were found to be less likely to write in



the diary compared to female family members. Factors such as gender and literacy appeared to influence diary use however this requires further investigation.

Exploring the use of diaries from multiple perspectives and experiences has provided valuable insight into the different ways in which diaries are used during and after the time in ICU demonstrating that although the diary is primarily written for the patient, family members, nurses and patients use the diary in different ways to support their needs and others needs throughout the experience of critical illness.

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# Declaration

I declare that this thesis has been composed by me, the research on which it reports is my own work and this has not been submitted for any other degree or professional qualification.

Signed: Corrienne McCulloch

Date: November 2017



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# Chapter 1 Introduction

## 1.1 Introduction

This introductory chapter describes the background to a qualitative study into the perspectives and experiences of patients', family members' and nurses' use of critical care diaries in an adult critical care unit in NHS Scotland, using a focused ethnography approach. Unlike earlier research where the focus has been primarily on the patient and family during recovery at home, here the focus is on experiences of critical care diaries from patients, family members and nurses during and after the time the patient is in intensive care. Using semi-structured interviews as the main source of data collection the researcher explored in depth the experiences and perspectives of study participants.

The background to the study will be given starting with experiences of critical illness and moving onto experiences of patients and families with critical illness. An explanation into the researcher's professional and personal interests in this area will be discussed and then an outline of the thesis will be given.

The terms critical illness, critical care and intensive care are used frequently throughout this thesis. Therefore, to avoid confusion with what is meant by these terms a short explanation will be given.

## 1.2 Critical illness

Critical illness is broadly defined within the literature as a life-threatening condition. Patients are classified according to the level of care they require in hospital, outlined in the Department of Health 'Comprehensive Critical Care' review (2000), see Table 1.



*Table 1: Classification of critical care patients (Department of Health, 2000, p.10)*

Level 0	Patients whose needs can be met through normal ward care
Level 1	Patients at risk of their condition deteriorating, or those recently relocated from higher levels of care, whose needs can be met on an acute ward with additional advice and support from the critical care team
Level 2	Patients requiring more detailed observation or intervention including support for a single failing organ system or post-operative care and those stepping down from higher levels of care
Level 3	Patients requiring advanced respiratory support alone or basic respiratory support together with support of at least two organ systems. This level includes all complex patients requiring support for multi-organ failure.

The Intensive Care Society have provided more detailed criteria with examples which can be found in a document ‘Levels of Critical Care for Adult Patients’ (Intensive Care Society, 2009), now due for review, however the updated criteria are based on the original levels of care listed in table 1. For the purpose of this thesis, critically ill patients are those who have required level 3 care (intensive care) during their hospital stay however it is acknowledged that level 2 (high dependency) patients may have similar experiences and needs.

### 1.3 A brief history of Intensive Care

Intensive care is a relatively new clinical speciality, originating from the pioneering work of anaesthetist Dr Bjørn Ibsen who developed a method of mechanical ventilation for critically ill polio patients at Copenhagen’s Blegdam Hospital during the acute poliomyelitis epidemic in the early 1950’s (Lassen, 1953). Dr Bjørn Ibsen has been credited with launching a ‘therapeutic revolution’ through providing mechanical ventilation outside the operating theatre on a large scale to treat patients over a prolonged time (Trubuhovich, 2004). During the polio epidemic, large numbers of patients were brought together in a group and treated in respiratory units where they received close and detailed monitoring from nurses (Crocker, 2007).

*“Nursing patients together was a technological innovation in itself, what made it successful was the fact that nurses adapted and developed*

*knowledge and skills to enable them to provide the detailed observation of critically ill patients with or without technological adjuncts.”*  
(Crocker, 2007, p. 329)

However, when the incidence of polio declined these units were closed and it was not until several years later in the 1960's that the first purpose-built Intensive Care Units (ICUs) opened in the United Kingdom (Woodrow, 2000; Crocker, 2007).

## 1.4 The Intensive Care Unit

The Intensive Care Unit (ICU) is

*“...a specially staffed and equipped, separate and self-contained area of the hospital dedicated to the management and monitoring of patients with life threatening conditions.”* (FICM/ ICS, 2013, p. 3)

Delivering a range of advanced therapies, monitoring and drugs, ICU is a highly technical and specialised area. Similar to other areas in the hospital, care is delivered using a multi-disciplinary approach. Medical, nursing and allied health professionals for example physiotherapists, dieticians and pharmacists, experienced in managing critically ill patients work together to deliver care. However, nurses are the largest group of healthcare staff working in the ICU.

Nursing care in this environment can involve nurses being present at the patient's bedside continuously, monitoring and delivering care to patients on a 1:1 ratio when they are critically ill, which is unique to the intensive care setting.

As recommended in the 'Core Standards for Intensive Care Units', developed by the Faculty of Intensive Care Medicine and the Intensive Care Society (FICM/ICS, 2013), a minimum ratio of one nurse to one patient (1:1 nursing) is required to deliver level 3 care and one nurse to two patients (1:2 nursing) to deliver level 2 care. Critically ill patients who require level 3 care are the 'sickest' patients in the hospital and this level of care is unique to the intensive care setting. Whereas level 2 patients can be treated in either an Intensive Care Unit (ICU) or a High Dependency Unit (HDU). Both of these areas independently, or in combination, are considered to be Critical Care units which is a more modern term in use following the publication of

the '*Comprehensive Critical Care*' review (Department of Health, 2000) mentioned earlier.

In this study, the focus is on people's experiences of critical care diaries written for level 3 patients. This group of patients are recognised in the diary literature as the main group that diaries are created for and are referred to as 'critically ill' or 'intensive care' patients, terms used in this thesis to describe the patient group and patient participants.

The unit where the study took place is referred to as a 'critical care unit' as it had a combination of level 3 and level 2 patients, however diaries were only started for patients in the level 3 area. Critical care is the modern term used to encompass intensive care, intensive therapy and high dependency units where patients with varying levels of critical illness are referred to for treatment. For the purpose of this thesis the terms 'critical care' and 'intensive care' will be used interchangeably as these terms are synonymous in the diary literature and the wider critical care community from which the researcher is part of.

## **1.5 Background**

The following sections provide background to the research starting with an overview of the experiences of critical illness and then introducing the concept of critical care diaries.

### **1.5.1 Experiences of critical illness**

Critically ill patients are supported and cared for in the ICU until they can be stepped down to a lower level of care. Supportive treatment in the ICU often involves advanced respiratory support from a ventilator or breathing machine during the critical phase of the illness. Sedation medication is given to keep the patient comfortable and safe while they require such invasive treatments. Depending on the illness trajectory and how the body recovers this can occur over a number of days or weeks, which can be prolonged further by secondary complications such as infection or delirium. After leaving ICU patients will continue to receive care in hospital until they are ready for discharge home. However, surviving a critical illness and being

discharged from ICU or hospital is only the start of the recovery process for patients and their families.

Patients experience a wide range of psychological and physical health problems impacting on recovery in the short and long term, with significant numbers of patients never returning to their original health status (Adamson, et al., 2004; Sukantarat, et al., 2007; Bench & Day, 2010). New and worsening impairments in physical, cognitive and mental health status after ICU discharge are defined as ‘post-intensive care syndrome’ (PICS) and with the addition of the word ‘family’ (PICS-F) can be applied to family members who may experience mental health problems (Needham, et al., 2012). The following two sections will explore in more detail the experiences of patients recovering from critical illness and the experiences of family members who are present throughout the time in ICU.

### **1.5.2 Patients’ experiences of critical illness**

Patients recovering from critical illness often have little or no memory of the events leading up to their illness episode and time spent in the ICU or hospital (Jones, et al., 2000; Samuelson, et al., 2006). Memories and recollections of factual events reported by patients following extubation are fragmented, patients remember events as fragments of sequences described as ‘jigsaw puzzle’ memory (Granberg, et al., 1998). The fragmentary nature of memories can leave the patient with little insight into how unwell they have been and lead to unrealistic expectations about their recovery whereas not knowing what has happened can be distressing for the patient (Bäckman & Walther, 2001; Roulin, et al., 2007; Paul & Rattray, 2008). Therefore, patients recovering from a critical illness may find it difficult to come to terms with what has happened and have been found to have a strong need to know throughout and after their stay in the ICU (Hupcey & Zimmerman, 2000).

Jones et al (2000), from a review of the literature on memory problems in ICU patients, suggest that there are two potential processes which can contribute to the memory difficulties patients experience. Firstly, the critical illness and treatment given in ICU can influence memories. Patients commonly experience sleep deprivation and delirium which can lead to amnesia and confusion. Furthermore, the

administration or withdrawal of certain drugs such as opiates or sedative drugs can have an effect on memory. Secondly, a process may exist moving the individual's attention from 'external stimuli' or events to 'internally generated images', thus enhancing memories such as hallucinations. Adamson et al (2004) report a variation in what patients are able to remember after ICU, with some patients having no memories and others being able to remember specific events. Lack of memory was more common and the authors suggest this is dependent on a number of factors similar to those identified by Jones et al (2000), as well as the possibility that memories may have faded through time with patients being interviewed at 6 months after their ICU admission (Adamson, et al., 2004). However, former ICU patients interviewed 10 years after their ICU admission continued to have memories containing strong emotions and memories of bodily sensations from when they were in ICU (Storli, et al., 2008). Therefore, although some memories may fade with time others continue to be present months and years after ICU admission and can have an ongoing effect on the person's life (Roberts & Chaboyer, 2004; Pattison, et al., 2007; Storli, et al., 2008).

During the early stages of recovery from critical illness, in the hospital and at home, patients find it difficult to distinguish dreams and illusionary experiences or hallucinations from reality (Papathanassoglou & Patiraki, 2003; Corrigan, et al., 2007; Cutler, et al., 2013). Trying to work out where memories occurred can be difficult for patients, who during this time step down from ICU to a lower level of care such as a hospital ward (Rattray, et al., 2010). Dreams, nightmares and hallucinations, referred to as delusional memories or unreal experiences, can be distressing for some patients and are associated with poorer emotional and psychological outcomes (Jones, et al., 2001; Rattray, et al., 2010; Wade, et al., 2013). A recent review of the evidence on psychological and neurocognitive consequences of critical illness highlighted that delusional and intrusive memories are one of the common psychological consequences of an admission to ICU alongside anxiety, depression and post-traumatic stress disorder (Clancy, et al., 2015).

Patients with delusional memories and no factual memory of real events occurring in ICU were found to have higher anxiety levels at 2 weeks post ICU discharge and

scored highly for post-traumatic stress disorder (PTSD) related symptoms and panic attacks at 8 weeks (Jones, et al., 2001). The results suggested that in the presence of delusional memories, the ability to remember real events even if unpleasant, may offer the patient some protection from the development of anxiety and PTSD related symptoms after ICU. Not all memories are distressing for patients and some patients have reported pleasant memories as well as unpleasant memories (Roberts & Chaboyer, 2004; Löf, et al., 2006). However, Samuelson (2011) suggests that pleasant memories are important for patients to relieve stress and counteract the impact of unpleasant memories from the ICU.

In the longer term, trauma patients who experienced delusional memories after ICU have been shown to have poorer health related quality of life and are more likely to have anxiety and depression at 5.5 years post injury in comparison to those who did not have delusional memories (Ringdal, et al., 2010). Guttormson (2014) has identified three distressing themes of the delusional memories ICU patients have, from a secondary analysis of data relating to sedation and mechanically ventilated patients' memories of ICU. Whilst secondary analysis of data has been identified by the authors as a limitation to the study, delusional memories emerged as an important aspect of the patient's ICU experience. The main themes include being held prisoner, a feeling of drowning or being strangled and being in a different country or world. Interestingly, the majority of patients in this study were reported to be restrained at some point during their stay which the authors note may account for memories of being held prisoner. However, physically restraining patients is not common practice in all ICUs therefore the specific types of delusional memories patients may have can vary. Nevertheless, patients' experiences of such memories being very real, scary and distressing are similar to findings in an earlier study by Löf et al (2006) where patients referred to their unreal experiences as 'horrific' and 'really terrifying' (p. 160). Löf et al (2006) interviewed patients at 3 and 12 months, post ICU discharge, to describe memories of factual events and unreal experiences relating to critical illness before, during and after ICU admission. Memories of unreal experiences and fragmentary memories of factual events from different stages of the critical illness journey did not really change between 3 and 6 months, however unreal experiences dominated patients' memories of ICU (Löf, et al., 2006).

Memories, experiences and psychological recovery from critical illness continue beyond discharge from ICU, impacting not only on recovery but on the individuals' life for weeks or even years after the event. Patients interviewed by Corrigan et al (2007), who tested positive for post-traumatic stress-reactions, expressed a need to understand their delusional and unreal experiences from ICU. They constantly thought about what happened however they were unable to make sense of this. Furthermore, patients who had no memories felt like they did not exist during this time which significantly affected them by preventing them from moving on. One of the main implications for practice raised from the studies discussed is the need for some patients to have an opportunity to talk about their experiences and memories following a stay in ICU.

While patients may have little recollection of what actually happened, their family members are witness to and 'live' the entire event (Paul & Rattray, 2008). As highlighted earlier, family members may experience mental health problems or psychological complications associated with exposure to critical illness, now recognised as PICS-F (Needham, et al., 2012; Schmidt & Azoulay, 2012). Symptoms can affect family members' general well-being, occurring during the time in ICU and for a long time after ICU (McAdam & Puntillo, 2009; Davidson, et al., 2012). A recent study conducted in Brazil comparing the incidence of anxiety, depression and PTSD symptoms in pairs of patients and family members during the ICU stay and at 30 and 90 days after ICU discharge concluded that family members suffered more than patients, with symptoms of anxiety, depression and PTSD higher in family members and continuing for a longer time (Fumis, et al., 2015). However, the study was carried out in a single private hospital with open visiting which the authors noted does not represent all ICUs in Brazil, or in fact other countries in the world. Additionally, there was a significant percentage of patients who were not included due to their poor status at ICU admission. Nevertheless, this study highlights the need to support both patients and family members during and after a stay in ICU.

### **1.5.3 Family members' experiences of critical illness**

With regards to family members, Nancy Molter's (1979) study on the needs of relatives of critically ill patients was the first study to be published in this area. Molter developed the Critical Care Family Needs Inventory (CCFNI), a questionnaire listing 45 need statements which can be divided into the five main areas of support, comfort, information, proximity and assurance (Holden, et al., 2002). Each statement was read to the participants and they were asked to respond on a scale of 1 to 4 with 1 being 'not important at all' and 4 being 'very important'. From the 40 relatives interviewed the most important need identified was to feel there was hope. This was followed by the feeling that staff cared about the patient and that sufficient and honest information was given, so for example relatives wanted to know about prognosis and to be contacted if there were any changes in the patient's condition. Furthermore, it was important for relatives to be near the patient. Criticisms of Molter's work relate to the structured interviews which were undertaken with only related family members, thus overlooking other family members. Furthermore, the CCFNI was developed from a review of the literature and a survey with graduate nurses, with no family member involvement, which may have led to certain needs or perceptions being missed (Holden, et al., 2002; Paul & Rattray, 2008). However, the CCFNI has been used internationally and replicated in a number of studies adding to the reliability, validity and further development of the questionnaire, as detailed in a review of the short and long term impact of critical illness on relatives by Paul and Rattray (2008).

Changes in family members' roles and responsibilities resulting from someone in the family being critically ill can place additional burdens on the family, especially during the early days of ICU admission (Johnson, et al., 1995) where family members are in shock and experience feelings of confusion, stress and uncertainty described by Jamerson et al (1996) as 'hovering'. In this early phase family members find it difficult to take in any information (Hughes, et al., 2005). Three further stages family members may go through during the time in ICU include 'information seeking', 'tracking' and 'garnering resources'. Jamerson et al (1996) found that as the initial shock settled family members began to actively look for information. Information seeking assisted family members to move on from the



hovering stage into being able to see the patient's progress. However, if information was insufficient the hovering phase continued. Through tracking, involving a process of observing, analysing and following what was going on, family members became aware of care and the environment they were in. Finally, garnering of resources involved family members meeting perceived physical and psychosocial needs of themselves and their ill family member. Jamerson et al (1996) explored family member experiences through unstructured interviews and one focus group at 2 – 6 months after discharge from a surgical trauma ICU. At the time the study was published there had been little qualitative research into the experiences of family members and a number of nursing interventions for the individual and organisation were highlighted for each stage. For example, in the seeking information stage anticipating the type of information family members need and providing regular updates are recommended.

Later qualitative studies exploring the experiences of family members and those close to the patient in ICU highlight further the needs of family members and ways in which they adapt to this situation. It has been reported that family members can be

*“...vulnerable and resourceful at the same time.” (Ågård & Harder, 2007, p. 170).*

Family members experience a range of emotions when they are with their loved one in ICU which can be overwhelming and the physical strain experienced from waiting around, travelling to and from the hospital and managing the demands of daily life during and after the critical illness episode can leave family members physically and emotionally exhausted (Eggenberger & Nelms, 2007). A sense of chaos has been described by family members when visiting the ICU as their feelings alternate between despair and hope (Eriksson, et al., 2011). They live in a constant world of uncertainty, not knowing what will happen next and wondering if their loved one will survive, adding to the suffering and vulnerability experienced by the family (Engström & Söderberg, 2004; Eggenberger & Nelms, 2007; Nelms & Eggenberger, 2010). Although family members are resourceful and find ways to cope with and adapt to the situation, they live with and endure the uncertainty. They prioritise their loved one's needs over themselves by being present which allows them to

demonstrate their love and support as well as sustain a relationship and they try to make sense of the situation through information seeking and tracking (Engström & Söderberg, 2004; Ågård & Harder, 2007; McKiernan & McCarthy, 2010), similar to that described by Jamerson et al (1996). However, family members need support to help them cope and it has been suggested that

*“Caring for the family is part of caring for the patient.” (McKiernan & McCarthy, 2010, p. 258)*

During the time in ICU it is important for family members to feel included which involves being present and observing the care given by professionals as well as participating in decisions and daily care (Frivold, et al., 2015). Furthermore, family members play a key role in supporting the patient throughout the critical illness journey, which in addition to taking on the role of surrogate decision maker in the ICU includes providing care and reassurance at home after discharge (Schmidt & Azoulay, 2012). Patients report feeling safe when their family are present in ICU and view them as important through offering hope, encouraging them to fight by giving them strength and a reason to stay alive, facilitating communication and understanding and re-orientating them to the outside world (Hupcey, 2000; Engström & Söderberg, 2007a). Family members have been described as a ‘lifeline’ for patients in ICU whose identity and individuality is threatened as a result of their critical illness and time in ICU (Bergbom & Askwall, 2000). Visits and presence from those closest to the patient can help to counteract this threat as they

*“...confirm the existence of the patient, their individuality, and their part in society and the world outside ICU.” (Bergbom & Askwall, 2000, p. 392)*

Furthermore, family members are viewed by nurses as an important source of information and a link to the critically ill person, helping them get to know the patient as a person and thus allowing them to provide care that is individualised (Engström & Söderberg, 2007b). Therefore, in addition to patients and their experience of critical illness, it is important to look at ways to support family members who, as highlighted, experience the critical illness together with the patient.

The terms relative, relatives, families, family member or family members have been used by authors to represent spousal relations, parents, siblings, other relations and close friends. A combination of these terms will be used throughout the thesis however, the terms family members and relatives will be used most frequently to encompass all relations.

## **1.6 Researcher's interest in Critical Care Diaries**

The concept of critical care diaries first came to the researcher's attention in 2010 at a local 'What's New in ICU?' study day for nurses and allied health professionals throughout the UK, hosted and organised annually by the Edinburgh Critical Care Research Group of which the researcher has been a member for many years. One of the invited speakers, Dr Christina Jones, introduced her work on diaries from a UK hospital (Jones, 2009) and spoke about a multi-centre randomised controlled trial by the RACHEL group looking at the effect of diaries on the development of PTSD (Jones, et al., 2010), sparking the researcher's initial interest into this area.

Working as a research nurse in critical care the researcher had daily contact with patients and family members at different stages of the critical illness journey. One study in particular, the RECOVER study (Walsh, et al., 2012), a randomised controlled trial comparing 'routine' ward care with enhanced rehabilitation, provided by a dedicated Generic Rehabilitation Assistant, involved following up patients weekly while they remained in hospital, up to a total of 12 weeks. Screening the medical notes and performing different measurements and assessments with post-intensive care patients opened the researcher's eyes to the early stages of recovery from critical illness. Furthermore, although the intervention was mainly targeted at physical recovery the researcher became aware of the psychological and emotional effects of having been critically ill in intensive care with patients voluntarily describing their experiences to her. In addition to previous nursing experience in intensive care and high dependency areas the researcher developed an interest in patients' and family members' experiences of critical illness and how to support these groups throughout the critical illness journey from the initial hospital and ICU admission to ongoing recovery at home.

Successful appointment in 2011 to the NMAHP Clinical Academic Research Career (CARC) Scheme in NHS Lothian (NHS Lothian, 2010) enabled the researcher to undertake the PhD part time with the Department of Nursing Studies at the University of Edinburgh.

At the time of designing the research in 2011/ 2012 and starting recruitment in 2013 diaries were not widely used in Scottish ICUs and for those units that were using or had used diaries the practice was relatively new. Therefore, this study was designed to address the gaps identified, provide insight into how diaries were being used in practice from the experiences of patients, family members and nurses in NHS Scotland and consider if and how we could use this nursing intervention in Scottish ICUs.

## **1.7 Outline of thesis**

This chapter has provided background information about critical care diaries and the need to explore this in NHS Scotland as well as outlining the development of the researcher's interest in critical care diaries, particularly from the experiences of patients, family members and nurses.

The remaining chapters are organised as follows. Chapter 2 provides a review of the literature. Chapter 3 gives a detailed account of the research design and methods, including ethical considerations and discussion around trustworthiness. Chapter 4 presents an overview of key findings from the research study presented as themes and sub themes identified from analysing the study data. Chapter 5 explores and makes sense of the findings, by highlighting key findings specific to each group, discussing findings in the context of diary research, other relevant literature and in relation to the concept of 'Stories as joint actions' thus answering the research questions and building on our current understanding and knowledge of critical care diaries. Chapter 6 concludes this thesis with discussion around limitations of the study, implications for practice and suggestions for future research.



## Chapter 2 Literature review

### 2.1 Introduction

The literature review chapter starts by examining the need to support patients and family members with the experience of critical illness, an issue raised in the introductory chapter of this thesis. An overview of the evidence for follow up services to support patients and their families following a stay in intensive care (ICU) and current recommendations on rehabilitation are presented. The provision of information is recognised as key to supporting patients and family members with the experience of critical illness and diaries providing individualised information about the ICU stay are identified as a nursing intervention which may help. Diaries are referred to in this thesis as critical care diaries or diaries and it is this nursing intervention on which the main body of the literature review is based.

Critical care diaries are introduced to the reader with an overview of the origin and incidence of this intervention throughout the world, which has seen it evolve and develop in different ways with different approaches used. Current practice with diaries is considered and presented using common themes identified from the literature. Having provided an in-depth overview of the more practical aspects of critical care diaries, research evaluating the effect of diaries on recovery from critical illness is addressed including recent studies in this area. However, the main interest is around experiences of diaries and therefore research exploring experiences with critical care diaries, available at the time of starting the PhD, is introduced. This leads the reader towards the rationale behind the proposed PhD research and the overall aim and research questions. Before moving onto the research design and methods chapter, discussion around potential theoretical perspectives to inform the research are introduced, followed by a summary of the chapter.

#### 2.1.1 Searching the literature

Sources for this literature review were identified through electronic databases including CINAHL, Medline, PsychINFO and the online search engines PubMed, DiscoverEd and Google Scholar. There was no date restriction applied when searching the diary related literature and only sources written in English were

included. Search terms used were ICU diary, patient diary, diary, intensive care, ICU, critical care, critical illness, recovery, follow-up, experience(s), perspective(s), patient, family, nurse and related terms e.g. family member, nursing. These terms were used in various combinations and additional sources were identified through reference lists of retrieved articles. Articles were mainly downloaded through the links provided on the electronic databases and search engines. For example, articles were downloaded from Wiley Online Library and Science Direct however, some were requested from the Edinburgh Interlibrary Loan service.

The initial review of the literature was conducted in 2011 and new sources added throughout subsequent years, as the popularity of critical care diaries continued to grow internationally. Furthermore, the researcher was part-time so wanted to keep up to date. However, during the process of gathering and analysing the data the researcher did not engage in depth with newer literature. Additionally, the researcher received regular email updates from the ICU diary network [www.icu-diary.org](http://www.icu-diary.org) as well as colleagues from the NHS and University forwarding on diary related literature, which the researcher often already had.

The overall process of searching the diary specific literature is presented as a PRISMA type flow diagram in figure 1, adapted from the PRISMA Group diagram used for systematic reviews and meta-analyses (Moher, et al., 2009).

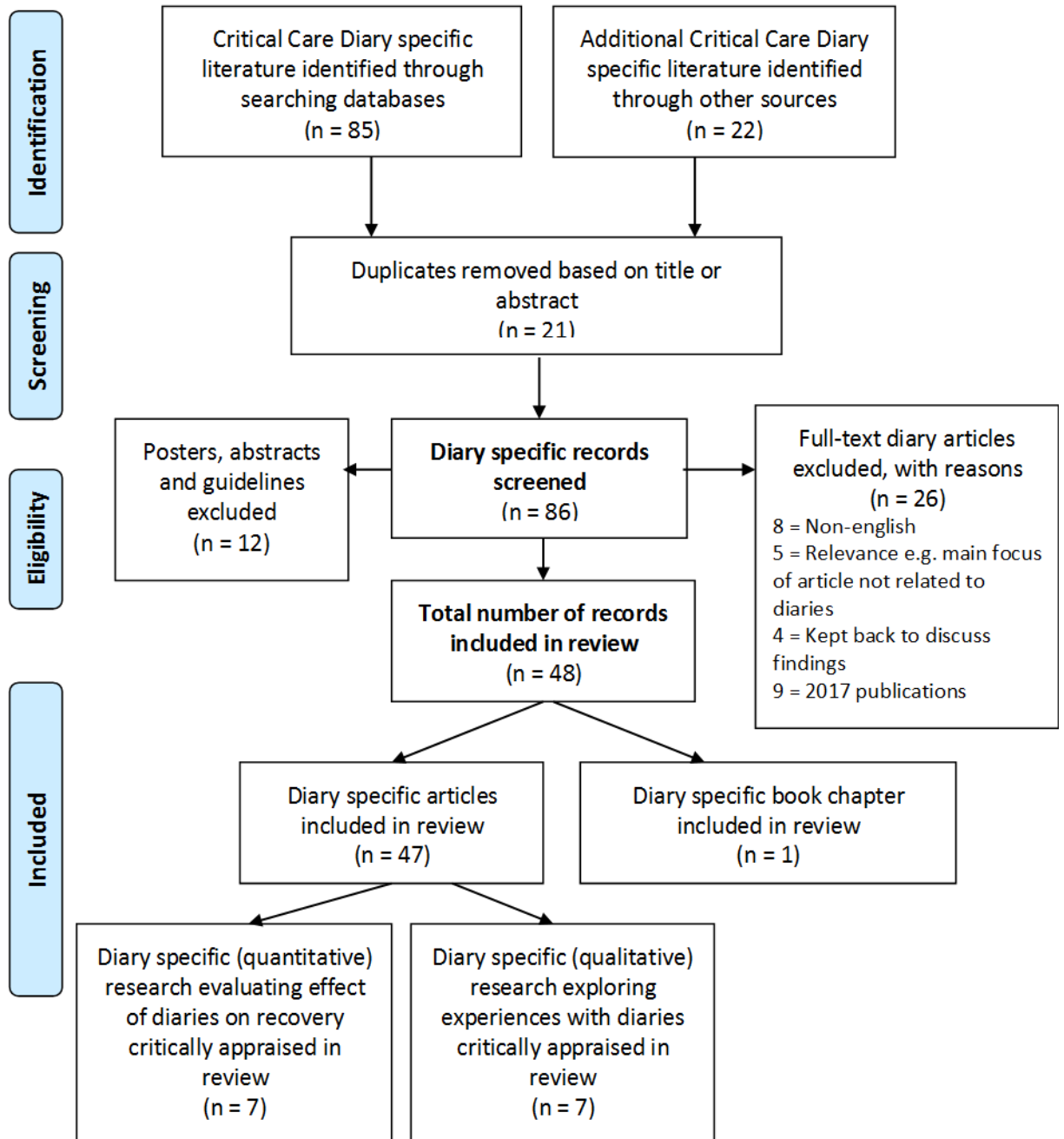


Figure 1: Diary specific literature search, PRISMA type flow diagram



## 2.2 Supporting patients and family members with the experience of critical illness

The Department of Health (2000) 'Comprehensive Critical Care' review recognised the physiological and psychological issues experienced following critical illness and highlighted the need for follow-up support in the United Kingdom (UK) stating that follow-up can

*"...complement the work of the intensive care unit and improve the speed and quality of recovery." (p. 16).*

Examples of units providing follow-up and benefits to patients and the service were given in the review. However, the ongoing development and availability of follow-up varies across the UK. A national survey by Griffiths et al (2006) found that only 30% of ICUs in the UK provided follow-up clinics for survivors of critical illness. The main reason given by units for not providing clinics was 'financial constraints' and from the 30% of ICUs that did provide clinics only 59% of these were funded. Research supporting follow-up is limited (Williams & Leslie, 2008) and various models of follow-up currently exist, as demonstrated in a Scandinavian survey of intensive care follow-up services (Egerod, et al., 2013). Furthermore, evidence supporting the effectiveness of interventions provided during follow-up is lacking, despite services such as clinics being around for several years (Lasiter, et al., 2016).

The PRaCTICaL study (Cuthbertson, et al., 2009) is one of the most notable studies discussed in the ICU follow-up literature. Findings from this UK study suggested that follow-up did not improve outcomes in ICU survivors. PRaCTICaL was a randomised controlled trial designed to evaluate a nurse-led intensive care follow-up programme versus standard care. However, from the primary and secondary outcomes measured, which assessed the effectiveness of the intervention on patients' physical and psychological recovery, there was no significant difference between groups. Cuthbertson et al (2009) concluded from the findings that there was no evidence to support either the effectiveness or cost effectiveness of follow-up for patients recovering from a critical illness. Several limitations to the study have been identified by the authors and others. Standard care for the control group was not defined, which has been said to affect external validity (Modrykamien, 2012).

Whereas the intervention started in the hospital and involved patients following a physical rehabilitation programme outlined in a manual prior to returning for follow-up. Although the intervention was introduced by a study nurse, patients monitored their own progress and compliance, leading to speculation about consistency in the intervention group (Cotton, 2012). Furthermore, the first follow-up appointment for the intervention group was not scheduled until three months after discharge, which the authors note may have affected the outcome and it is now recognised that patients value support in the early stages of recovery from healthcare professionals (Prinjha, et al., 2009; Deacon, 2012). Additionally, the overall study sample size (n=286) has been criticised for being small and including only patients requiring level 3 care who are generally the sickest patients in the ICU (Cotton, 2012).

In contrast, qualitative research evaluating ICU follow-up has demonstrated benefit to patients in terms of their physical, emotional and psychological recovery (Prinjha, et al., 2009). Prinjha et al (2009) conducted a qualitative study focusing on patients' experiences and perceptions of follow-up services in the UK. 34 patients who had received treatment in ICUs from across the UK were interviewed about different aspects of their illness experience. It was found that patients valued follow-up as they received continuity of care, information, expert reassurance and an opportunity to give feedback to ICU staff. Having the opportunity to discuss and find out the real and the delusional from memories allowed patients to 'move on' and helped their anxiety levels. Furthermore, Prinjha et al (2009) reported on the type of information patients wanted and although many patients had received general handouts and information at discharge, they reported particular benefit from information that related directly to them and their condition, which for some patients was supplemented with a diary, written during the time they were in ICU. In trying to make sense of their experience, information about their illness, the procedures and treatments they went through, their progress and dates recording these were all very important. The authors note that some patients were interviewed several months or years after they had received follow-up, which was highlighted as a limitation to the study. However, experiences described by participants often presented in more than one account which the authors suggest support the findings.

Follow-up has allowed a greater understanding of what happens to patients and their families during recovery from critical illness and in 2009 the National Institute of Clinical Excellence (NICE) issued a clinical guideline, 'Rehabilitation after critical illness' (NICE, 2009). The guideline makes several recommendations to improve the rehabilitation of general critical care patients. The need for patient centred care i.e. taking into account patients' needs and preferences and the provision of information and support for patients and their families features strongly throughout the care pathway. NICE recommend that the provision of information should be tailored to the individuals' needs, culturally appropriate, accessible to those with additional needs and available for families and carers. All these aspects of information provision are important to ensure that patients and their families are able to make informed decisions about their care and treatment during and after a stay in ICU (NICE, 2009).

Hupcey and Zimmerman (2000) explored experiences of critically ill patients and the 'need to know' using a grounded theory approach. The findings indicated that after the event patients wanted information about what happened and if information was lacking they felt frustrated and took it into their own hands to try and piece together the story. This process involved patients spending a significant amount of time and energy asking a range of healthcare professionals and family members questions about what happened. Sometimes information appeared to be withheld from patients or they would forget what they had previously been told. Family members were the main people patients relied on to fill in the gaps however, as highlighted in the Introduction chapter of this thesis, being in the ICU is an emotional time for family members. Therefore, family members may still be coming to terms with their own experience and unable to discuss events from the ICU or may try to protect the patient by not sharing information even though this can help the patient understand what they have been through (Jones & Griffiths, 1995; Jones & Griffiths, 2007). Furthermore, one of the most important needs of family members during their relative's critical illness and stay in the ICU is the need for information (Verhaeghe, et al., 2005; Paul & Rattray, 2008). During visiting, families value interaction with staff and continuous information about their loved one, leading to the formation of a 'trusting relationship' with staff which is very important to the family (Eriksson, et

al., 2011). There is then an undeniable need to provide support and information for both patients and their families during and after a stay in ICU.

One initiative highlighted in the NICE (2009) clinical guideline is the provision of a diary, kept for the patient while they are in ICU and it is this nursing intervention that is the main focus of the literature review. Diaries are referred to in the NICE (2009) clinical guideline as

*“...a way to deliver information to both the patient and their families and/ or carers” (p. 59)*

More recently, ‘Guidelines for the Provision of Intensive Care Services’ from the Faculty of Intensive Care Medicine (FICM) and the Intensive Care Society (ICS) refer to diaries as an aid for optimising recovery from critical illness which requires

*“...a multi-professional and multiple therapy approach.” (FICM/ ICS, 2015, p. 58)*

One key recommendation around rehabilitation is that patients and family members are given the opportunity to record their experience so that they can begin to reflect on this during the time in hospital and as stated in the guidelines:

*“This may take the form of diaries, either paper or electronic, and may include photos, videos and written information. This material may be collected prospectively or retrospectively depending on the desire of the patient and family.” (FICM/ ICS, 2015, p. 59)*

However, at present this recommendation is only for high-risk or complex patients and therefore does not consider the needs of the family during the time in ICU.

Nevertheless, the guidelines recommend diaries as a possible initiative to provide information which can support patients’ psychological and cognitive recovery from critical illness (FICM/ ICS, 2015). Furthermore, the Scottish Intensive Care Society Audit Group Minimum Standards and Quality Indicators for Critical Care in Scotland recognise the importance of meeting the rehabilitation needs of patients and involving the family in the review process as well as meeting family members’ informational needs which can help support emotional needs (SICS 2015).

Therefore, a diary, containing information which is accessible to both patients and

family members is potentially one way of providing support for those experiencing critical illness and thus requires further exploration to understand how this intervention may work.

## **2.3 Critical Care Diaries**

### **2.3.1 Introduction to diaries**

Diaries are currently being used in some intensive care units (ICUs) to help patients with their recovery following the experience of a critical illness. In this context, the diary gives an account of the time spent in ICU, written for the patient while they are critically ill. Diaries are initiated by nursing staff within the first few days of admission to the unit when the patient is sedated, ventilated and expected to have a prolonged stay. The diary is written at the bedside by nurses caring for the patient and visiting members of the patient's family, who are encouraged to write. The diary does not contain clinical information about the patient that would normally be written in their medical notes. It is a factual account or narrative of the patient's stay in ICU written to and for the patient from the perspective of the bedside nurse and visiting family members. Following discharge, the diary is handed over to the patient for them to read and refer to during their recovery.

### **2.3.2 Origin of diaries**

The original idea to keep a diary for patients came from a project introduced at a Danish hospital in 1984, according to Nordvedt (1987) as cited in Bergbom et al (1999). This project was known as 'dialogue in nursing' and Egerod et al (2011a) report that it involved sharing nursing notes with patients to promote patient freedom and involvement in care. Originating in the Scandinavian countries, diaries have now been kept for ICU patients since the early 1990's (Egerod, et al., 2007; Åkerman, et al., 2010; Gjengedal, et al., 2010). A comparative international study examining the emergence and evolution of diaries in Scandinavia demonstrated that diaries were introduced across Denmark, Norway and Sweden as a 'grass-roots' initiative by nurses who worked in and shared ideas between different ICUs (Egerod, et al., 2011a). Several schools of thought were found to inspire diaries, which have been referred to as a therapeutic instrument, an act of caring, an act of empathy or a hybrid of all three (Egerod, et al., 2011a).

In Denmark, the diary was initiated as an 'intuitive experimental approach' by nurses who wanted to help patients with their experience following ICU discharge, there was no evidence available at this time to support the practice apart from accounts of former ICU patients who revisited the hospital (Egerod, et al., 2007). Whereas in Norway and Sweden, nurses undertaking academic work in the area of diaries lead the way, positive feedback from patients and their families continued to be the most compelling factor for maintaining and developing diaries in ICUs (Egerod, et al., 2011a). Local nurses using their own initiative to implement diaries in their units have been responsible for this intervention and the subsequent generation of knowledge and research, which has spread internationally through conferences, publications and training (Egerod, et al., 2011a). Thus, inspiring others to implement and provide what appears to be an important nursing intervention in critical care.

### **2.3.3 Incidence of diaries**

There continues to be a growing interest in the use of diaries for ICU patients and their families, represented by the recent number of articles, including literature reviews and research studies as well as abstracts published at international conferences. An increasing number of countries are now represented in the diary literature, as outlined in Table 2, however, a significant number of publications continue to come from the Scandinavian countries of Norway (Storli, et al., 2003), Denmark (Egerod, et al., 2011b; Nielsen & Angel, 2016) and Sweden (Engström, et al., 2008; Bäckman, et al., 2010; Åkerman, et al., 2013; Glimelius Petersson, et al., 2015; Johansson, et al., 2015), including joint collaboration between the three countries (Egerod, et al., 2011a). Other European countries represented include the United Kingdom, France, Germany, Switzerland, Italy, Portugal and Austria (Roulin, et al., 2007; Jones, et al., 2010; Garrouste-Orgeas, et al., 2012; Nydahl, et al., 2015; O'Gara & Pattison, 2016; Heindl, et al., 2016). Additionally, Australia, the United States of America and Japan have reported diary use (Ewens, et al., 2014; Nair, et al., 2015; Fukuda, et al., 2015; Locke, et al., 2016).

*Table 2: Countries represented in diary literature*

Scandinavian Countries			
Denmark	Norway		Sweden
Other European Countries			
Austria	France	Germany	Italy
Portugal	Switzerland		United Kingdom
Non-European Countries			
Australia	Japan		United States of America

An international diary network was established in 2012, co-founded by Eva Åkerman, Carl Bäckman, Ingrid Egerod, Christina Jones, Dirk Knüick, Peter Nydahl and Sissel Storli. The network is based online at [www.icudiary.org](http://www.icudiary.org), providing support, information and an opportunity to connect and collaborate with other healthcare professionals interested in diaries. Furthermore, several countries have conducted national surveys to determine the extent and application of diaries, beginning in Denmark with Egerod et al in 2006 (Egerod, et al., 2007) and followed by Sweden, Norway, Germany, Australia and most recently Austria (Åkerman, et al., 2010; Gjengedal, et al., 2010; Nydahl, et al., 2010; Nair, et al., 2015; Heindl, et al., 2016). The national surveys from the Scandinavian countries are comparable in that Sweden and Norway replicated the original nationwide survey conducted in Denmark with only slight adjustments and modifications for each country. The Scandinavian surveys were conducted using a semi-structured interview on the telephone. All ICUs were contacted to determine if they used diaries or not and those found to be using diaries were then invited to participate in the survey. Nearly all units using diaries participated, with only one unit in Norway and one unit in Sweden not completing the interview. From contacting the ICUs, it was found that 40% in Denmark (Egerod, et al., 2007), 44% in Norway (Gjengedal, et al., 2010) and 76% of ICUs in Sweden (Åkerman, et al., 2010) used diaries.

The survey was conducted in Germany in 2008 including only 2 of 16 federal states due to researcher resource, the size of the country and number of ICUs in comparison to the Scandinavian countries (Nydahl, et al., 2010). The number of ICUs (n=120) contacted was greater than the total number of ICUs in Sweden (n=86), which contains the largest number from the Scandinavian countries. It was unexpectedly found by Nydahl et al (2010) that diaries were not in use in any of the ICUs contacted, despite Germany sharing the south border of Denmark. The Scandinavian researchers used one method to make contact whereas the researchers in Germany used multiple methods, both telephone and mail, which they argued increased the internal validity of the survey. Furthermore, they were confident with their design as it compared to other German studies which had produced positive results through surveys and interviews (Nydahl, et al., 2010). Reasons given for the unexpected results were attributed to the language barrier, including the fact that the majority of



diary literature is written in English, limitations in the nursing education system and the absence of ICU aftercare or follow-up which has been frequently associated with diary use in other countries such as the UK and Scandinavia (Prinjha, et al., 2009; Egerod, et al., 2013). For example, in the UK diaries were introduced in the early 2000's as part of follow up programmes, providing aftercare to patients and families who had experienced a critical illness (Combe, 2005; Robson, 2008; Prinjha, et al., 2009).

Nydahl et al (2015) repeated the German survey in 2014 following the introduction of diaries in 2008 by two of the authors. On this occasion 152 ICUs from the 2 federal states previously surveyed were contacted and emails sent to a further 69 nurses in other parts of Germany who had expressed an interest in the study. From this, 43 ICUs were found to be using diaries, six years after implementation first began in Germany. However, the authors acknowledge that it is still unknown the number of ICUs using diaries in Germany as less than 13% of ICUs were surveyed and the 2 federal states may not be representative of other states in Germany regarding diary use (Nydahl, et al., 2015).

The Australian survey by Nair et al (2015), adapted from the original Danish survey was conducted slightly differently to the others. In addition to modifications being made for the Australian setting the survey sample was selected through the Australian College of Critical Care Nurses using an online survey portal. From 2400 members 1563 had previously expressed an interest in being contacted about research and from this group there were 194 respondents to the survey. The authors report that the majority of respondents were non-diary users and the survey was conducted from the perceptions of individual nurses rather than individual units, as in the previous surveys, which meant that it was difficult to compare results. However, results from this survey demonstrated that from the nurses who completed the survey only 19% (n=37) were currently using diaries in their ICU. The authors note that the use of diaries is only beginning in Australia and should not become common practice until further research is carried out to determine the impact, format and handover processes of diaries. Furthermore, Nair et al (2015) call for a greater understanding around the psychological impact of diaries on patients and family members to

determine if diaries are beneficial. This view is shared by a group of researchers from the UK and Australia who have raised concern around the current evidence available to evaluate the effectiveness and safety of diaries for patients and families recovering from the experience of critical illness (Ullman, et al., 2015).

Finally, Austria is the most recent country to have explored the extent and application of diaries (Heindl, et al., 2016), replicating Egerod et al's Danish survey (Egerod, et al., 2007). All ICUs in Austria (n=178) were contacted and 7.3% (n=13) were found to be using diaries. Diary use in Austria began in 2012 and as with the other surveys informants from ICUs using diaries were invited for interview. An interview guide developed by Nydahl et al (2015) for the second German survey was used, uncovering two main themes of nurses' experiences with diaries: the process of innovation and the process of practice. Diaries were viewed as a new nursing intervention in Austria and the authors note that consulting nurses in the early phase of implementation is a strength of the survey as it adds to knowledge around the process of diary implementation.

The national diary surveys have been conducted to describe and compare the extent and application of diaries in different countries throughout the world. Replication of the original survey by Egerod et al (2007) demonstrates a growing interest in this area, as highlighted at the beginning of this section. This collection of surveys and the findings, although not described in detail here, have provided information on the background to implementing diaries in each country as well as revealing the extent of this nursing intervention and the differences in practice between different countries and ICUs. Therefore, providing evidence of diary use and spread within and across countries. However, whether countries were established in using diaries or not all the authors recognised the need for further research and to develop national diary guidelines to address the differences in practice between ICUs, which will be discussed further in the following section. Egerod et al (2007) suggest that the development of guidelines for diaries

*"...should help solve the problem of inhomogeneous practice and pave the way for research." (p. 166)*

The main areas for future research identified by the authors include: exploring the effect of diaries on ICU survivors and their families using qualitative and quantitative approaches such as randomised controlled trials (Egerod, et al., 2007; Nydahl, et al., 2010; Nydahl, et al., 2015); patient selection, diary structure, content and use (Åkerman, et al., 2010); the patients' perspective on diaries (Gjengedal, et al., 2010); impact, format, handover processes and the psychological impact of diaries on patients and families (Nair, et al., 2015) and finally the process and outcome of diaries (Heindl, et al., 2016).

## **2.4 Current practice with diaries**

The practice of using diaries for critically ill patients has continued to evolve and develop through uptake in different units and countries. A recent Cochrane systematic review by Ullman et al (2015), which was published after designing and conducting this research, supports earlier findings by the researcher from an initial review of the literature. Variation exists in how diaries are used, the common characteristics of the diary and the methods used to study diaries has made it difficult to make comparisons (Ullman, et al., 2015). Furthermore, a lack of underlying theory to conceptualise and rationalise the use of diaries has led to the recommendation that diaries are not routinely implemented into clinical practice (Aitken, et al., 2013). Despite the different approaches there are some common themes evident in the literature, relating to the process and practice of the diary intervention in critical care which will now be discussed, incorporating more recent literature. These include the intended patient group or population, authoring the diary, content, photographs, handover and maintaining and establishing diaries in practice.

### **2.4.1 Patient group**

Patients who are sedated, mechanically ventilated and expected to remain in ICU for at least 48 hours are the main group of patients that diaries are kept for, as they can experience issues with memory following an admission to ICU (Egerod, et al., 2007; Åkerman, et al., 2010; Gjengedal, et al., 2010; Beg, et al., 2016). Critically ill patient groups currently represented in diary research include adult medical, surgical and mixed ICU populations. Whereas patient groups currently excluded from diary

research and therefore not represented are those with neurocognitive impairment including pre-existing and new conditions, prior psychological or mental health problems, visual impairment and patients who do not speak the primary language of the country where the research is being conducted (Beg, et al., 2016). Beg et al (2016) note that patients with prior psychological or mental health issues could potentially affect results of studies investigating the impact of the diary on psychological or cognitive recovery therefore it makes sense to exclude them. However, Beg et al (2016) also recognise that these patient groups are likely to be at the highest risk of developing such problems and could benefit the most from such an intervention. Current research and discussion around the impact of diaries on psychological recovery will be presented later in the review, see section 2.5.

Evidence currently available on the impact of diaries on specific patient groups and their families in critical care and during recovery is greatly lacking. Similar to patients currently excluded from diary research, there may be specific needs over and above the general ICU population that could be supported through the use of a diary. Critically injured military personnel treated in military camps and hospitals are a specific ICU patient group where diaries have been introduced (Thomas & Bell, 2011; Hester, et al., 2016; Locke, et al., 2016). This group of patients are unique in that the majority of them have experienced and are suffering from extremely complicated and traumatic injuries, they may be coping with the injury or death of colleagues and are transferred often thousands of miles from where their initial injury occurred to an appropriate ICU (Hester, et al., 2016). Each one of these experiences alone can be life changing and take time to come to terms with. However, the current evidence available for using diaries in this patient group is limited.

Thomas and Bell (2011) described the introduction of diaries for military personnel in a UK hospital, reporting that from an evaluation of the project there had been positive feedback from patients and families. However, little information was provided about how the evaluation was carried out other than identifying those who were involved, including a specialist defence nurse and her team. There is no explanation about how the diaries were used in terms of when and where they were started, who the main authors were, if photographs were used and when and how the

diaries were handed over, however the authors report guidelines were developed. Despite this Hester et al (2016) refer to this evaluation as evidence supporting diary use with this patient group and in particular patients who initially receive treatment in a 'combat ICU' before being transported away from the war zone to another ICU. Hester et al (2016) carried out a survey with ICU nursing staff before and after the introduction of diaries in a combat ICU in Afghanistan. Diaries were perceived by the nurses as beneficial to patients, their families and nurses working in this area. The survey was limited to nurses, with a small sample size (n=16 pre-implementation and n=10 post-implementation) and diaries were introduced for a very short period of 2 to 3 weeks before the post-implementation survey was completed, which the authors acknowledge are all limitations mainly resulting from 'competing operational demands' such as staff changing on a regular basis and the challenges of providing care in this environment (Hester, et al., 2016).

While traditionally being targeted at long-term, sedated and mechanically ventilated patients, diaries have been introduced with short-term, awake and non-invasively ventilated patients (Egerod, et al., 2011a). It is recognised that patient groups who wish to gain an insight into their illness journey along a continuum of time or those who have similar experiences to mechanically ventilated and sedated critically ill patients may benefit from this intervention (Egerod, et al., 2007; Egerod, et al., 2011a).

Hayes & Kelly (2008) in the UK introduced diaries into a critical care oncology unit where patients were not sedated or ventilated, however experienced symptoms such as memory loss and anxiety. Patients who received a diary were contacted by telephone at one month after discharge to find out if the diary had been of value to them, using a semi-structured questionnaire. Although 15 patients had a diary started, 7 went home with their diary and only 4 were able to give feedback. Despite this small group evaluation, feedback was similar to that given by ICU patients as the diaries helped patients in understanding their illness and what had happened during their admission to the oncology unit by filling in memory gaps and as a result allowed them to be more realistic in setting goals for their recovery. Diaries in this

setting were seen as a useful aid alongside other strategies in supporting patients who had been exposed to a distressing event (Hayes & Kelly, 2008).

### **2.4.2 Authoring the diary**

The diary is started in the ICU and written prospectively at the patient's bedside. However, there is significant variation in the optimum time to start a diary, ranging from 24 to 72 hours after admission to the ICU (Egerod, et al., 2011a; Ewans, et al., 2015). Diary writing is mostly undertaken by nursing staff and family members, with other healthcare professionals and close friends contributing to this process (Bäckman & Walther, 2001; Roulin, et al., 2007; Jones, 2009). For example, there is evidence of a combination of family members, friends, nurses and other healthcare professionals such as ICU physicians writing in the diary from the countries listed in section 2.3.3.

The incidence of different groups authoring the diary appears to be determined by the individual unit and a difference in practice has been noted between countries (Egerod & Christensen, 2010). For example, in a study by Egerod and Christensen (2009), exploring the structure and content of diaries in Danish ICUs, it was found that although participation from families was allowed, nurses discouraged this so there were no written entries from family members in the diaries analysed. Furthermore, in a reported 40% of Danish ICUs participating in diary use only half of these ICUs encouraged family participation (Egerod, et al., 2007). Family participation has previously been reported as controversial in Denmark due to ethical and legal issues such as protecting the privacy of patients and the potential for misuse of the diary by family members (Egerod & Christensen, 2009). However, Egerod et al (2011b) have suggested that the need of family members to remain close to their loved one could be met through co-authoring the diary or keeping a separate diary.

In the last few years and after the design and implementation of this PhD study, an interest has developed with family members and diary writing. Research relating to diaries and the psychological wellbeing of family members (Jones, et al., 2012; Garrouste-Orgeas, et al., 2012) is discussed later in this literature review chapter, see section 2.5.3. Whereas research exploring the experiences of family members with

diaries (Garrouste-Orgeas, et al., 2014; Johansson, et al., 2015) and perceptions of relatives who were invited to write their own diary for the patient while they were in ICU (Nielsen & Angel, 2015a; 2016) is included in the discussion chapter.

The responsibility for initiating diary writing and continuing this process throughout the ICU stay lies with ICU nurses who are considered as the main authors (Egerod, et al., 2007; Gjengedal, et al., 2010). This has been noted in a recent systematic review of diaries to promote recovery for patients and family members after critical illness (Ullman, et al., 2015), even though others are invited to contribute such as family members who have been found to write more than nurses in one study (Garrouste-Orgeas, et al., 2012). Patients are generally unable to write in the diary due to their compromised condition, including altered consciousness, weakness and physical impairment (Egerod & Christensen, 2009). Therefore, the diary is unable to provide a personal account of the critical illness journey from the perspectives and experiences of the patient (Egerod & Christensen, 2009). However, the diary is written to and for the patient thus acknowledging and demonstrating the presence of the patient throughout the experience of critical illness (Roulin & Spirig, 2006).

Finally, with regards to authoring the diary it has been reported in the literature that occasionally diaries have been continued following discharge from the ICU up until death or discharge from hospital (Bäckman, et al., 2010; Ewens, et al., 2014). However there has been no research to support this, other than patients in a UK study suggesting that this might be one way the diary intervention could be improved (Robson, 2008).

### **2.4.3 Content**

The diary provides details of what happened when the patient was in ICU, it tells an ongoing story (Egerod & Christensen, 2010). It is often started with a summary of the events and reasons for admission to the ICU, which are considered important in helping the patient understand how they became critically ill (Jones, 2009). An introduction to the purpose of the diary can also be explained at this stage (Gjengedal, et al., 2010). Examples of events observed throughout the ICU stay that are documented in the diary include: the patient sitting out in the chair for the first

time; descriptions of everyday routines and nursing care; reactions from the patient; and significant other events that might be considered important to the patient such as who has visited, what is happening at home and what the patient's family is thinking and feeling (Bäckman & Walther, 2001; Roulin, et al., 2007; Egerod & Christensen, 2009). In addition to written information, diaries may include photographs from different stages of the patient's illness trajectory (Bäckman & Walther 2001), however photographs will be discussed separately in the next section, 2.4.4.

Nurses experienced in using diaries recommend that entries written by healthcare staff are written in a personal style, addressed to the patient, contain simple language and avoid medical jargon or meaningless writing (Bäckman & Walther, 2001; Gjengedal, et al., 2010). Whereas relatives are encouraged to write about what is happening at home and if they wish, their own feelings however if this information is felt to be too personal to share with other family members and staff it can be written on a separate sheet, sealed in an envelope and kept with the diary until the patient wishes to read it (Jones, 2009). A loose-leaf system is preferred in some units as pages can be removed easily if text needs to be rewritten or additional content becomes available, such as a painting from a child who is at home or any written communication from the patient to others in the ICU (Combe, 2005; Gjengedal, et al., 2010).

While many similarities are described internationally on the content of diaries, as seen with other aspects of the diary there is little evidence to support and inform this (Aitken, et al., 2013). Furthermore, as with authoring the diary, discussed in the previous section 2.4.2, different practices occur in different ICUs and countries.

#### **2.4.4 Photographs**

Photographs are described as an 'essential part of the diary' (Egerod & Bagger, 2010), used as a visual aid alongside text in the diary to help patients understand their illness (Jones, et al., 2010; Åkerman, et al., 2013). The photographs are taken throughout the ICU stay, including individual and more generic photographs. Examples of photographs reported in the diary literature include the patient lying in bed; significant events involving the patient; family members and nursing staff



beside the patient at the bedside; aspects of the physical environment containing equipment; and photographs from the patient's perspective, for example a picture of the ceiling above the bed (Roulin, et al., 2007; Bäckman, et al., 2010; Jones, et al., 2010). Including family members and staff in photographs can be comforting for patients as when they look back on their time in ICU this demonstrates the presence of others, thus reassuring the patient that they were not left on their own (Bäckman & Walther, 2001).

Despite the potential benefit of photographs for the patient there are issues, both legal and moral, that relate to taking a photograph of an unconscious adult without their prior consent (Egerod, et al., 2007) and in some ICUs this practice is not permitted (Nydahl, et al., 2015). Consideration must be given to whether the patient would want to see themselves in this situation which is not an easy decision to make, as the views of the family and nurse can often be different to that of the patient (Jones, 2009). However, if photographs are to be used in the diary, it is recommended they are taken with sensitivity and that there is an intention to respect the dignity of the patient (Gjengedal, et al., 2010). Additionally, photographs should be kept in a secure place until the patient can give retrospective consent, at which point the photographs can be handed over (Jones, 2009). However, some ICUs store photographs in a sealed envelope at the back of the diary and others insert photographs directly into the diary as they are taken with an explanation written about each photograph (Egerod, et al., 2011a). Furthermore, if the patient does not survive some ICUs will offer the diary and photographs to the patient's family (Bäckman, 2002) whereas other ICUs will only offer the diary, as the patient never consented to photographs being taken (Jones, 2009).

There is debate around the use of more sensitive photographs. For example, in Sweden some ICUs believe that photographs of injured patients or those with a changed appearance can help during recovery whereas other ICUs would avoid taking such photographs (Åkerman, et al., 2010). The researcher heard about this practice first hand when visiting a hospital in Sweden in 2013 where ICU nursing staff in one of the ICUs reported taking photographs of necrotic fingertips and toes prior to amputation as some patients found this useful in coming to terms with why

they had undergone surgery for amputation. A more recent study by Åkerman et al (2013) on the preferred content and usefulness of a photo diary found that photographs helped patients understand the extent of their critical illness by completing the story and confirming written content. This was a mixed methods study using a questionnaire (n=115) and interviews (n=15) with patients 6 months after discharge from ICU. From the questionnaire findings, most patients did not find their photographs unpleasant to look at (69%), however a similar percentage (70%) indicated that there was no need for photographs of wounds or injured body parts. Therefore, the use of more sensitive photographs and photographs in general requires further research.

The content of photographs, frequency and number of photographs taken during the ICU stay and whether photographs should be kept separate from the diary are all examples of unanswered questions in the literature. Furthermore, a review by Aitken et al (2013) on the use of diaries in psychological recovery from ICU suggested that different methods towards the use of photographs in diaries, for example generic photographs of the ICU environment versus specific photographs of body parts may lead to different outcomes.

#### **2.4.5 Handover**

The patient does not tend to receive their diary until after discharge from the ICU or hospital. Knowles & Tarrier (2009) suggest that there might be an ‘optimum therapeutic window’ for the patient to receive their diary however this has not yet been determined. Research studies evaluating the effect of diaries on recovery from critical illness have handed over diaries at various time points and locations including ICU discharge (Glimelius Petersson, et al., 2015), 1 week after ICU discharge (Fukuda, et al., 2015), hospital discharge (Garrouste-Orgeas, et al., 2012) and at follow-up visits between 2 – 12 weeks after ICU discharge (Knowles & Tarrier, 2009; Jones, et al., 2010; Bäckman, et al., 2010). However there has been a lack of rationale and no theoretical or empirical justification for the timing of diary handover (Aitken, et al., 2013).

In practice, the way in which the diary is currently handed over is agreed within the individual unit and can be influenced by how diaries have evolved and been introduced in each country. For example, in Denmark it has been found that some units give the diary to patients at discharge without any plans for follow up or time to go through the diary with them (Egerod, et al., 2007; Egerod, et al., 2011a). Whereas in Norway and the UK diaries have been handed over to patients later in their recovery as part of a structured follow up appointment (Storli, et al., 2003; Jones, 2009). However, other factors such as resources available at a local level have seen a variation in the practice and incidence of diary use (Robson, 2008; Hale, 2010; Nydahl, et al., 2015).

Meeting with a nurse has been reported as an important aspect of the diary intervention, especially when handing the diary over to the patient (Bergbom, et al., 1999). The diary literature identifies a variety of nursing staff involved in handing over the diary, ranging from those who have cared for the patient to others in more specialist or senior roles. Whatever the role, the nurse must be cautious when handing over and guiding the patient through their diary for the first time as it is likely to contain some information that the patient may find distressing such as descriptions of their struggle to survive, unrecognisable photographs and other events they were unaware of, which can all provoke strong emotions (Engström, et al., 2008; Storli & Lind, 2009). Therefore, it is recommended that an experienced nurse is present to go through the diary, ensuring that the patient understands its contents and an opportunity is given for the patient to ask questions (Bergbom, et al., 1999; Jones, et al., 2010; Phillips, 2011). Nursing skill and availability is a resource on which the success of diaries clearly depends, addressed in the following section on maintaining and establishing diaries in practice.

### **2.4.6 Maintaining and establishing diaries in practice**

The presence of a 'diary group' and nursing staff who are willing to regularly write in the diary, support relatives to write in the diary and take photographs of significant events are imperative in establishing and maintaining the quality of the diary whilst the patient is in ICU (Storli, et al., 2003; Gjengedal, et al., 2010; Hale, 2010; Jones, et al., 2010). Nursing staff can be encouraged to engage in the diary intervention

through feedback from patients and their families and by becoming involved in the handover of diaries (Robson, et al., 2006). In addition to feedback, staff education and supervision is also fundamental to the success of implementing diaries (Hale, 2010). However, in a busy ICU where there are many pressures on staff, including lack of funding and resources to support this intervention, this can be somewhat difficult with other clinical issues taking priority (Robson, et al., 2006; Hayes & Kelly, 2008). This intervention despite for the most part only involving a few minutes of nursing time per day to update the diary (Jones, et al., 2010) does increase the workload of nursing staff (Egerod, et al., 2007).

## **2.5 Research evaluating the effect of diaries on recovery from critical illness**

While diaries have been around for nearly 30 years it has only been in the past decade that research studies have emerged demonstrating the benefits of diaries on a larger scale and in relation to patient outcomes during recovery. Research evaluating the effect of diaries on recovery from critical illness has highlighted the potential benefit diaries may have in relation to psychological recovery, emotional wellbeing and quality of life (Knowles & Tarrier, 2009; Jones, et al., 2010; Bäckman, et al., 2010). At the time of designing the PhD study most research focused on the use of diaries for patients during their recovery from critical illness. However, an interest in the effect of diaries on the psychological well-being of family members has been seen in recent years (Jones, et al., 2012; Garrouste-Orgeas, et al., 2012). Although this research was not completed or published at the time of designing the PhD study due to the lack of research available, it will be incorporated into the review along with two more recent studies looking at diaries and their effect on memories (Fukuda, et al., 2015; Glimelius Petersson, et al., 2015).

### **2.5.1 Psychological and emotional wellbeing in patients**

The first randomised controlled trial to study the effect of a prospective diary kept by nurses and family members during a stay in ICU was conducted in the UK by Knowles and Tarrier (2009). This was a single centre study using the Hospital Anxiety and Depression Scale (HADS) to assess symptoms of anxiety and depression in patients post intensive care. 36 patients were recruited and assessed at

two time points, approximately 1 month post ICU discharge and then 3 weeks later. The intervention group were given their diaries after the first assessment and the control group after the second assessment. The diary was handed over to all participants by an experienced ICU nurse consultant who had advanced level training and education in communication, having undertaken a Masters degree in clinical practice and a basic counselling course. The session lasted up to 60 minutes with the nurse reading through the diary together with the patient and answering any questions. It was found that diaries had a significant positive impact on symptoms of anxiety and depression at two months following ICU discharge.

However, Knowles and Tarrier (2009) have been criticised for not differentiating between what aspect of their intervention influenced the patients' wellbeing. Querques (2009) argues there is a possibility that a verbal feedback session with the patient about the care they received in ICU might be just as effective and require less time and effort than producing a diary. Furthermore, it could be argued that the advanced communication skills and training of the nurse handing over the diary may have had an impact. Finally, a total of 52 patients were approached to take part in the study however some patients approached did not want to see their diaries as they wanted to forget about what happened and the authors related this to avoidance behaviour seen in PTSD. However, it is possible that patients who declined were comfortable with their experiences and did not feel it necessary to dwell on what happened by reading this in a diary.

A subsequent international multi-centre randomised controlled trial of 352 patients referred to as the RACHEL study, by Jones et al (2010), evaluated the effect of a prospective diary on the development of new onset PTSD three months after ICU discharge. The authors believed that a diary written to explain what happened to the patient during their time in ICU would provide a context for delusional memories, fill in gaps and thus aid psychological recovery. Participants were recruited around one week after discharge from ICU when they were assessed using the ICU Memory Tool (ICUMT). Prior to randomisation, at one month, and then again at three months the Post Traumatic Stress Syndrome (PTSS-14) screening tool was completed and at three months the PTSD Diagnostic Scale (PDS). Patients in the intervention group

received their diary between one and two months following ICU discharge whereas, participants in the control group received their diary after the final assessment at three months. Follow up at three months showed the occurrence of new onset PTSD related symptoms was significantly lower in the intervention group, 5% compared to 13% in the control group. However, a number of criticisms have been made regarding the outcome measures and how they were performed in this study as well as having a follow up period of only three months (Aitken, et al., 2013; Ullman, et al., 2015).

Further analysis by Jones et al (2010) suggested that patients with high levels of PTSD symptoms at one month following ICU discharge would benefit most from this intervention. In addition to the findings, intervention patients reported reading and rereading their diaries several times which is thought to be therapeutic (Egerod, et al., 2007) as it has the potential to reduce distress by enabling the patient to modify the way they think about their experience (Jones, et al., 2010). Furthermore, when participants were asked what helped the most, 49% reported that reading the diary text was most important, 36% identified the combination of photographs and text, 15% preferred the photographs and only 1.4% of patients (n=2) mentioned the meeting with the nurse. However, reporting participants' views on what was most helpful about the diary does not differentiate between what aspect of the diary intervention potentially influenced the incidence of new onset PTSD related symptoms after ICU discharge.

### **2.5.2 Quality of life**

A third study evaluating the effect of diaries on recovery from critical illness was conducted by Bäckman et al (2010) from Sweden, who is well known for conducting one of the early research studies on diaries (Bäckman & Walther, 2001), which will be discussed in the following section on experiences with diaries. Bäckman et al (2010) conducted a prospective, non-randomised study which was part of a larger study examining health related quality of life (QoL) after critical illness across 3 ICUs in Sweden. They found that patients who received an 'ICU diary' and a follow up visit after discharge from ICU scored higher in a health related QoL questionnaire during the 36 month follow up compared to those who did not receive a diary. The

health related QoL outcome measure used was the Medical Outcomes Study 36-Item Short-Form (SF-36). A total of 499 patients across the 3 units were included in the main study from which 38 (95%) of the diary group responded and 224 (49%) of the no diary group (n= 459) responded.

The authors acknowledge that the lower response rate in the group who did not receive a diary may cause a bias when estimating the effect of the diary however they noted that those who responded were representative of this group as there were no significant differences when compared to those who did not respond. Whereas the group that received a diary and follow up visit (n= 40) were from a single centre, which regularly used diaries. Phillips (2011) and Ewans et al (2015) have noted that between the diary and no diary group there were differences in the severity of illness and age thus raising question about the reliability and validity of the findings. Furthermore, as with findings from the previous two studies by Knowles and Tarrier (2009) and Jones et al (2010) it is difficult to determine what aspect of the diary intervention, provided alongside a follow up service, influenced the outcomes. Nevertheless, this study adds to the existing evidence available on the impact of diaries on patients. Firstly, by using a health related QoL outcome measure (SF-36) which has never been used to measure the effect of diaries before and secondly by following up patients for 36 months, whereas other studies have had a shorter follow up period.

### **2.5.3 Psychological wellbeing in family members**

After designing this PhD study, two studies emerged suggesting that diaries may benefit family members by preventing PTSD. The first of these studies is a sub study from the RACHEL trial discussed earlier. Jones et al (2012), in addition to main study with patients, looked at the effect of diaries on PTSD related symptoms in close family members. The study sites involved were from the UK and Sweden, 2 of the 12 recruiting sites involved in the RACHEL study. A total of 36 family members were recruited between the two sites with 30 completing the study. 15 family members were in the intervention group where patients could receive their diary from one month after ICU discharge and 15 were in the control group. Similar to the patients in RACHEL, family members were assessed prior to randomisation at

one month after ICU discharge with the PTSS-14 and then again at 3 months. It was found at the 3 month follow up assessment that family members of patients in the intervention group had lower levels of PTSD related symptoms than family members of patients in the control group.

The authors considered this to be a pilot study due to the small sample size. However, they suggest that providing a diary to patients at one month into their recovery may help psychological recovery in their family members (Jones, et al., 2012) yet it is unclear how the diary actually helped family members. Family members were invited to write in the diary during the time in ICU however it is unknown how many family members from each group participated in diary writing. Furthermore, this research did not consider the effect of family member diary use during the time in ICU as it was focused on recovery from critical illness and diary use after the time in ICU. Neilson and Angel (2015b) in a systematic review, report from personal communication with Jones that at one of the recruiting sites there was interaction between family members and staff at the time of handing over the diary which may have influenced the results. Jones et al (2012) recognise that there may be several explanations for the results and call for further research to look at the different mechanisms of the diary.

The second study was a French study by Garrouste-Orgeas et al (2012) using a before and after cohort design to measure the impact of a diary, written by family members and staff, on psychological well-being of patients and family members at 3 and 12 months after ICU discharge. 143 patients were recruited with 48 in the pre-diary period, 49 in the diary intervention period and 46 in the post-diary period. In addition to the patient participants, one family member for each patient was recruited. At ICU discharge family members completed the HADS and Critical Care Family Needs Inventory. Study follow up occurred over the phone at 3 and 12 months, post ICU discharge. Patients and family members completed the HADS and Peritraumatic Dissociative Experiences Questionnaire at 3 months. Then at 12 months they completed the Impact of Events Scale-revised questionnaire, a screening tool for PTSD measuring posttraumatic stress-related (PTS-related) symptoms. The main impact on psychological well-being in patients and family members was seen



after 12 months with PTS-related symptoms decreasing significantly in family members and surviving patients from the diary intervention group.

Interestingly, the biggest improvement was seen in family members. The authors believe that the diary may counteract some factors associated with psychological symptoms in family members after ICU discharge. For example, they suggest the diary provides information that is understandable and accessible which may help family members who have a lack of understanding of information given by healthcare professionals. Furthermore, Garrouste-Orgeas et al (2012) in addition to the main study analysed the content of all 49 diaries in the intervention group and found that from 5208 sentences, 59.8% were written by family members. Furthermore, 34.3% of all the sentences written in the diaries described feelings and emotions which was the largest category of sentences. Given that family members contributed the most entries it is possible to conclude that they were responsible for these entries, as others writing in the diaries were nurses and nursing assistants, responsible for 22.7% of sentences and physicians who were responsible for 17.4%.

There are various limitations to this study identified by the authors (Garrouste-Orgeas, et al., 2012), including that it was a single centre study and did not use an RCT design like other diary studies. However, they were concerned about cross contamination during the intervention period which is why they chose a sequential design (Garrouste-Orgeas, et al., 2012). Another criticism of the study is that around 20% of patients were excluded as their relatives were not available at the time of discharge from ICU which Stevenson (2012) notes introduces the possibility of selection bias and limits the findings being generalised to patients who do not have 'actively engaged relatives'. Furthermore, the drop out of patients and family members from all groups during the follow up period has been noted (Nielsen & Angel, 2015b), with less patients than family members completing the study. However, it would appear from the flow chart of the study (Garrouste-Orgeas, et al., 2012, p. 2035) that the main reason for patients being lost to follow up was death.

### 2.5.4 Memories

Finally, two recent studies from Japan and Sweden, published after completion of the PhD study, looked at diaries and their effect on memories, which can be linked to psychological recovery from critical illness, outlined in the Introduction chapter, see section 1.5.2 Patients' experiences of critical illness.

Researchers from Japan (Fukuda, et al., 2015), report on a study evaluating the effectiveness of diaries in improving “distorted memories” encountered during an ICU admission and relieving acute stress symptoms. This study was a non-randomised controlled trial with two periods of data collection, starting with the control group (n=23) who received normal care and followed by the intervention group (n=17) who were given a diary in addition to normal care. Patients in both groups were assessed at 1 week post ICU discharge and then prior to hospital discharge with the ICUMT, HADS and Acute Stress Disorder Scale (ASDS) which as explained by Fukuda et al (2015) is a tool used to screen for acute distress disorder.

This study in comparison to other reported in this review had the shortest time for follow up. Furthermore, the diaries which were received only by those in the intervention group were given after the first assessment at 1 week post ICU discharge while the patients were still in hospital, thus using the diary as an early intervention post ICU. Additionally, participants in the intervention group were interviewed prior to hospital discharge to explore how they used the diary and how they felt about it. The authors reported decreased HADS and ASDS in the intervention group prior to hospital discharge and an improvement in distorted memories. Limitations included a small sample size, non-randomised controlled design and a lack of longer term follow up however, these limiting factors were attributed to this being the first-time diaries had been used in Japan and the absence of a long term follow up service for patients after ICU (Fukuda, et al., 2015). Furthermore, the diary was handed over by a researcher who read through it with the patients, reflecting on events from the ICU. Patients in this group were interviewed prior to the final assessment. However, it is unclear if either of these activities may have affected the results. Finally, the authors explained that the diaries were taken away from patients following their final study

assessment and those who wanted their diary could have it posted out, yet there was no account of how many of the 23 patients wanted their diary after the study was complete.

Whereas, Glimelius Petersson et al (2015) from Sweden found that there was no significant difference in memories at 2 months post ICU discharge between patients who received and read their diary and patients who did not receive a diary. The ICUMT (Swedish validated version) and the PTSS-14 were completed at 2 months post ICU discharge. In addition to this, a short questionnaire evaluating the diary was given to those who received a diary. A total of 96 patients were recruited with 52 receiving a diary and 44 not receiving a diary. 40 in the diary group and 34 in the no diary group completed the 2 month assessments. From the evaluation of diaries, it was found that diaries appeared to be valuable for understanding what happened, even though they did not contribute to memories of the ICU stay, which were recorded as factual, emotional and delusional memories in the ICUMT. Diaries were viewed as an act of caring and a tool to open-up discussion with family members after ICU. The study was conducted in an ICU where diaries and a nurse led follow up clinic were already routinely used for patients expected to have a length of stay (LOS)  $\geq 3$  days. Therefore, participants were not randomised to the study, which the authors acknowledge in addition to the small sample size are limitations (Glimelius Petersson, et al., 2015). Furthermore, even though the control group with no diary was selected from patients with a LOS stay  $\geq 3$  days the diary group had a significantly longer LOS.

In summary, while diaries have shown potential in aiding psychological and emotional recovery from critical illness for patients and family members there has been concern about the evidence base, including a lack of research to determine the risks associated with diary use (Phillips, 2011). This appears to be an ongoing issue and despite the incidence of positive findings various limitations exist such as small sample sizes, length of follow up and being unable to determine what aspect of the intervention influenced the wellbeing of patients and family members. For example, an experienced ICU nurse handing over the diary, reading through the diary with the patient or attending follow up. Furthermore, Aitken et al (2013) note inconsistencies

in the selected samples, study outcome measures and a lack of clarity around how the intervention is provided. However, it is acknowledged that the diary may serve a different purpose for family members and as highlighted in this section there has now been interest in looking at how the diary may benefit family members.

## **2.6 Research exploring experiences with critical care diaries**

Research exploring experiences with critical care diaries started with two early studies published from Sweden (Bergbom, et al., 1999; Bäckman & Walther, 2001), the first research to be published on diaries in ICU. Followed by two studies from the UK (Combe, 2005; Robson, 2008) and then further qualitative research from Sweden and Denmark, which explores experiences of diaries in more depth (Engström, et al., 2008; Egerod & Bagger, 2010). Finally, one study from Denmark using grounded theory method to explore patients' and family members' use of diaries after a stay in the ICU is considered (Egerod, et al., 2011b). Only research published prior to the design and implementation of the PhD study will be included in this section, as it was within this context that the study was designed. The researcher however acknowledges that there has been an increase in research published since starting the PhD in 2011, which will be included in the Discussion chapter of the thesis when explaining the findings from this PhD study, 'Critical Care Diaries: a qualitative study exploring the experiences and perspectives of patients, family members and nurses.'

### **2.6.1 Early research exploring experiences with diaries**

Earlier observational studies from Sweden by Bergbom et al (1999) and Bäckman and Walther (2001) used questionnaires to investigate experiences of the patient and family with diaries. Bergbom et al (1999) reported that patients filled in the 'lost' time from reading the diary which helped them come to terms with what had happened, however some patients said they would have liked photographs. Family members of deceased patients (non-survivors) were given the opportunity to receive the diary and reading it made them realise just how unwell their loved one had been. This was a small study consisting of 10 patients and 4 out of 8 relatives of non-survivors. The questionnaires were created and assessed for relevance by

experienced nurses working in the unit with no input from patients or families. It could be argued that this study did not truly reflect the opinions and feelings of the patients and their families because what a nurse thinks is important to ask about diaries could be significantly different to what is important for the patient and their family. Nevertheless, these findings were supported further by Bäckman & Walther (2001) who also used questionnaires to explore the use of a diary as an aid in debriefing patients and relatives following critical illness.

Bäckman and Walther's (2001) study had a significantly larger sample size with 41 patients and 10 relatives of non-survivors receiving a diary. Furthermore, the diaries in this study contained photographs. The main focus of the questions was on how often the diary was read, who read the diary and how the writing and photographs contained within the diary were perceived. All the questionnaires sent at 6 months, following ICU discharge, were completed and returned by either the patient or their relative. The diaries were shared with relatives and friends and read several times, apart from one respondent who did not feel ready to read the diary. Otherwise responses from patients and relatives of non-survivors regarding the content of the diary were positive suggesting that diaries, including photographs, can help patients and their relatives understand their illness and recovery through reconstructing memories, consistent with other work in this area (Storli, et al., 2003; Robson, 2008; Jones, et al., 2010). It is interesting to note that this study was initiated and supported by an enthusiastic group who had a genuine interest in the psychological outcome of ICU patients. They acknowledge that this might have influenced the response rate to questionnaires however it could also be argued that the presence of the team in the ward and at hand over might have influenced how the diaries were used and experienced by those receiving them. Recognised as one of the first published studies in this area, Bäckman & Walther (2001) continue to be frequently cited in the literature.

### **2.6.2 Research from the UK exploring experiences with diaries**

Implementation of diaries in the UK was seen in the early 2000's with the introduction of follow up clinics for patients after intensive care, as reported in a

pilot study by Combe (2005) examining retrospective and prospective diaries.

Combe (2005) introduced prospective diaries based on Bäckman and Walther's (2001) study, having previously tried retrospective diaries. The retrospective diaries, although helpful in giving information about the ICU stay, were experienced by patients as impersonal and difficult to relate to. Furthermore, they were very time consuming to assemble with information gathered by the ICU follow up nurse from the medical notes. Therefore, the decision was made to use prospective diaries that included photographs and the project was given ethical approval as a service improvement initiative. It was reported that feedback had been positive from patients, family members and staff. The benefits of diaries included a better understanding of what had happened in the ICU, more realistic goal setting during recovery, improved communication between patients and their family members and providing comfort for bereaved family members. Combe (2005) describes this project as a pilot study however there was a lack of detail on the methods used. For example, what methods were used to collect and analyse the data. Furthermore, there were no quotes from patients or bereaved family members to provide evidence for the findings.

A few years later, Robson (2008) published an evaluation of diaries in ICU. In contrast to Combe (2005), the methods were outlined including a postal questionnaire and in depth interviews. However, it was only the questionnaire findings of the study that were reported. Robson (2008) noted that questionnaires were designed to record patient's experiences with diaries and posted out to all surviving patients who had received a diary in the first two years following implementation. From 36 questionnaires 20 were returned (56%). All patients who responded had had their diary for at least 6 months however, it is not clear if questionnaires were posted to patients in possession of a diary for less than 6 months. As noted by Combe (2005) some patients were unable to read their diary until 3 months after being in ICU so it would have been interesting to know if this was similar in the sample recruited by Robson (2008).

In keeping with findings from the previous studies mentioned, patients found the diaries helpful in understanding what had happened when they were in ICU,

including what it was like for their families (Robson, 2008). However, it was also found that some patients experienced distress when reading their diary for the first time. Reasons given for this included the realisation of how unwell they had been and how bad things were for them and their family, seeing or reading things that they had no recollection of and feeling vulnerable when they read the diary. It has been acknowledged by others that despite the initial distress, resulting from reading a diary, patients find security and comfort in their diary when they are feeling anxious or depressed and continue to read their diary well into their recovery thus enabling them to see how far they have come and to move on (Bäckman & Walther, 2001; Combe, 2005; Engström, et al., 2008). Another finding by Robson (2008) was that most patients who responded (85%) would have liked their diaries to continue after they had been discharged from ICU. The reliability and validity of the questionnaire was never established and had never been piloted, which has been acknowledged as a limitation. Furthermore, Robson (2008) cautions that some patients may have chosen not to respond due to the distressing nature of re-visiting their ICU experience and recommends further in depth research into patients' experiences of diaries.

### **2.6.3 Patients' experiences with reading a diary**

Following on from earlier research, two qualitative studies were conducted on patient experiences with diaries from Sweden and Denmark. Engström et al (2008) from Sweden were the first to conduct an in depth qualitative study on patient experiences with diaries. Twenty-two former ICU patients were contacted at least 2 months after ICU discharge and 9 agreed to participate. Interviews using a narrative approach were conducted around 1 year after ICU discharge and analysed using a qualitative content analysis approach. The main theme emerging from the content analysis was 'touching a tender wound' with four different categories in this theme: being afraid and being deeply touched; appreciating close relatives' notes; a feeling of unreality; and gaining coherence. One of the main findings from this study was that reading the diary for the first few times can be painful and demanding for patients. However, patients expected it to be difficult to read the diary and the strong feelings experienced eased with time. Entries written by family members were appreciated as patients learned about family members visiting the ICU and their experience. Yet,

parts of the diary content were experienced as being unreal, with patients reporting that it was as if they were reading about someone else. In keeping with earlier studies, the diary gave a sense of coherence to patients about the ICU stay including how unwell they had been and what happened to them. Therefore, the authors suggest the diary could work as a tool to help patients make sense of their critical illness experience.

Engström et al (2008) highlight limitations of their study, noting that interviews were conducted in Swedish however findings from the analysis were translated into English which they state may have affected the findings. Furthermore, this is a qualitative study and it is acknowledged that whilst findings cannot be generalised they provide further understanding of patients' experiences with diaries which might be useful in other situations.

The second qualitative study on patients' experiences of diaries was a sub study from the RACHEL trial (Jones, et al., 2010), discussed earlier in section 2.5.1. Egerod and Bagger (2010) conducted a focus group with 4 former ICU patients and created narratives of each individual diary to provide context for responses from participants. There were two participants included from each group in the RACHEL study, the control group who received their diary after 3 months and the intervention group who received their diary after one month. Therefore, unlike the study conducted by Engström et al (2008) patients' experiences of diaries were based on how diaries were used in the RACHEL study, rather than in clinical practice. A semi structured thematic interview guide was created from the literature and data from the focus groups were analysed using an inductive coding technique. Codes and sub-codes were presented under each theme, which appeared to be based on the themes used in the interview guide.

Findings from the study highlighted that the diary was an incomplete source of information and reading the diary did not help to bring back memories, however it did help patients to construct their story or illness narrative thus helping them to make sense of their critical illness experience (Egerod & Bagger, 2010). Patients therefore needed to know what they had been through and wanted to share this with family members. Recommendations from the study were on improving the diary



intervention by including more detailed information in the diary such as patient behaviour, involving family members in writing the diary and individualising the timing of diary handover. The number of participants recruited in this study is noted as a limitation by the authors however, attempts had been made to recruit between 6 and 8 participants for the focus groups, having started out with 10 possible participants. On the day of the focus group 4 participants dropped out as they were not feeling up to participating, which highlights the vulnerability of this group and some of the difficulties in conducting research in this area.

#### **2.6.4 Constructing the illness narrative**

The diary as a source of information was explored further in a qualitative study using grounded theory method by Egerod et al (2011b) in Denmark, who looked at how patients and their families used diaries in the context of the illness trajectory. The study was conducted using a grounded theory approach at 6 to 12 months following ICU discharge, thus enabling data to be generated from different stages of the illness trajectory. 19 patients and 13 relatives from two Danish ICUs were recruited and data gathered by using in depth semi-structured interviews. This is the first qualitative study to include paired relatives of patients who survived critical illness, as previous research has appeared to only include bereaved relatives (Bergbom, et al., 1999; Bäckman & Walther, 2001; Combe, 2005). However, as with the previous study by Egerod and Bagger (2010) discussed in section 2.6.3, this was another sub-study of the RACHEL study.

Diaries were written and kept by nursing staff until handover to the patient at either 1 or 3 months post ICU discharge, as per the RACHEL study protocol. Findings revealed that patients used the diary, alongside other sources of information, to gain insight and construct their illness narrative which helped them to progress in their recovery. Relatives supported patients throughout this process, with some relatives negotiating access to the diary to aid healing after living through their ‘own trauma’. The written part of the diary as a source of information was found to be limited however, Egerod et al (2011b) highlighted from their findings that the diary acted as a vehicle through which conversation was initiated. Therefore, allowing the patient to acquire further information and insight into their experience. The findings from

this study are significant as the focus was on how the diary was used in the wider context of recovery. Diaries were recommended as

*“...a low-technology, low-cost rehabilitative intervention for patients and relatives to help bridge the span from intensive care to recovery.”*  
(Egerod, et al., 2011b, p. 6)

In summary, research exploring experiences with critical care diaries has contributed to our understanding of what it is like for the patient to receive and read their diary. For example, patients have reported being afraid to start reading their diary as they expect it to be difficult and can find it difficult to continue as they begin to understand what happened which is often upsetting, including learning about what their family members have been through (Bergbom, et al., 1999; Engström, et al., 2008). Furthermore, some patients choose to avoid reading their diary for a while (Combe, 2005; Robson, 2008) or begin to read it from the end (Engström, et al., 2008). Nevertheless, when patients read their diary it helps them understand what happened in the ICU and they can use this information to come to terms with the experience of critical illness (Bergbom, et al., 1999; Bäckman & Walther, 2001), through constructing their illness narrative (Egerod & Bagger, 2010; Egerod, et al., 2011b). Furthermore, patients can share information from the diary with family members which can help to improve communication (Bergbom, et al., 1999; Combe, 2005; Engström, et al., 2008) and information in the diary can support bereaved family members (Bergbom, et al., 1999; Bäckman & Walther, 2001; Combe, 2005).

The main purpose of the diary is to help the patient with their recovery from critical illness. However, an ongoing need has been identified by authors in the field to provide further research from the patient and family experience (Robson, 2008; Engström, et al., 2008; Egerod, et al., 2011a). Learning from the experiences of patients and their families has been essential for the ongoing practice of diaries, demonstrated during the early years when diaries first appeared in the Scandinavian countries and nurses realised the potential of them through feedback from patients returning to the ICU after discharge (Egerod, et al., 2007). However, as noted in this review, research on experiences with diaries has mainly been conducted in the Scandinavian countries. Furthermore, at the time of starting the PhD and as reported

in this section, there is a lack of research conducted in this area, with little research focusing on experiences of family members and no research exploring the experiences of nurses.

## **2.7 Rationale behind proposed research**

As noted in this review, studies conducted in this field have focused mainly on the use of the diary during the patient's recovery from critical illness, which is what the diary is primarily aimed at. However, as discussed, the diary begins in the ICU where it is written and read daily by the patient's family and nurses at the bedside, yet little is known from nursing and family member perspectives and experiences during this time. For example, how they use the diary and the impact of the diary on them individually and in relation to each other, including the patient.

The diary as a nursing intervention in ICU has been promoted as patient centred, written for and to the patient personally, thus acknowledging the 'patient as a person' (Gjengedal, et al., 2010). The diary can be a valuable tool for providing care and improving practice, with nurses in one unit reporting that writing in a diary makes them more aware of how 'unique' each patient is and through this process they see the patient in 'a new light' (Storli, et al., 2003). No other document exists addressing the patient directly in a personal and supportive manner about their experiences and the events occurring in ICU (Egerod & Christensen, 2010). Thus, the presence of the diary in ICU demonstrates one way in which nurses can work towards providing person centred care and develop a relationship with the patient in ICU as the diary requires the nurse to connect with and focus on the person whilst considering their individual needs and experiences in ICU.

An anecdotal account by Stenson (1996) illustrating the use of diaries in neonatal ICU to promote attachment between the mother and baby inspired the researcher to think about how diaries are used with adults in ICU. The diary in the neonatal setting took the form of letters written by nursing staff from the baby's viewpoint, which were attached to the incubator for parents to read. Some parents were found to have written letters back to their babies and nursing staff and it is believed that this assisted in communication and development of 'supporting relationships' with staff.

In the adult setting, when diaries are co-constructed by families and nursing staff, perceptions of the ICU experience are shared with the patient. A central theme of sharing throughout the ICU time was identified along with four sub themes of sharing the story, sharing the presence, sharing feelings and sharing through support from a content analysis of 8 diaries in a Swiss ICU (Roulin, et al., 2007). In this context, it has been suggested that the diary might be able to help support families by involving them in care and maintaining the relationship with their loved one, whilst also acting as a medium to promote communication with healthcare staff (Roulin, et al., 2007). Therefore, although the diary's primary function is to assist the patient during recovery from critical illness it could be argued that it serves a purpose in providing patient and family centred care through communication, interaction and the development or maintenance of relationships between families, patients and nursing staff in the ICU.

It is argued that the diary is a valuable resource to patients and potentially family members, yet the way in which it is currently used and the potential to enhance communication, interaction and relationships during critical illness and recovery is not fully recognised or understood. To begin to understand what is happening here, the researcher proposes gaining an understanding simultaneously from the perspectives and experiences of nurses', patients' and family members' use of diaries. Thus potentially offering a unique insight that has not been explored before. The research questions:

- What is the patient experience of having a diary?
- What is the nurse experience of using a diary?
- What is the family member experience of using a diary?

have been developed to meet this aim and explore the phenomenon of experiences with critical care diaries. The research design and methods used are outlined in the following chapter.

## 2.8 Theoretical perspectives

In developing this research various theoretical perspectives were considered. A detailed account of the chosen theoretical perspective of Symbolic Interactionism and how this fits in with the study of experiences of critical care diaries is provided in the following chapter on research design and methods. However, the diary is essentially a story of the patient's journey through critical illness (Roulin, et al., 2007; Egerod & Christensen, 2009) and used by patients to construct their illness narrative or story (Egerod, et al., 2011b) after the critical illness. Therefore, in this final section of the literature review the researcher will introduce the concepts of illness narratives, stories and storying.

### 2.8.1 Illness narratives

Critical care diaries have traditionally been used for patients during their recovery to explain and understand the critical illness and time spent in ICU. Co-written by nurses and family members in the ICU setting, diaries share some common features with illness narratives.

Illness narratives are a specific type of story concerned with the theme of illness. They can be about illness episodes, illnesses or illness experiences and are created by either the person who is ill, members of their family or a healthcare professional (Hydén, 1997). They occur in various social contexts, for example institutional or everyday contexts, take on different forms such as oral or written narratives and have different uses (Hydén, 1997), outlined in Figure 2.

1. To transform illness events and construct a world of illness;
2. To reconstruct one's life history in the event of a chronic illness;
3. To explain and understand the illness;
4. As a form of strategic interaction in order to assert or project one's identity; and
5. To transform illness from an individual into a collective phenomenon.

*Figure 2: Illness narrative uses (Hyden, 1997, p. 55)*

There has been an increasing interest in the study of illness narratives across the social sciences, humanities, healthcare and medical professions (Bury, 2001). Earlier influential studies by Kleinman (1988) and Frank (1995) are cited as helping to establish illness narratives as an area for study (Atkinson, 2009). Kleinman's (1988) book *The Illness Narratives: suffering, healing, and the human condition*, is based on more than 20 years of clinical experience, with an interest in how people live with and respond to chronic illness, leading to a series of studies on the experience of illness. Different aspects of illness meanings are presented by Kleinman, who notes that in the context of chronic illness,

*"The illness narrative is a story the patient tells, and significant others retell, to give coherence to the distinctive events and long-term course of suffering."* (Kleinman, 1988, p. 49)

Hydén and Brockmeier (2008) however, observe that Kleinman's main interest is with listening to and making sense of narratives to improve clinical practice, rather than with the patient's personal narrative. Whereas Frank (1995; 1997) in his work with illness narratives, uses his own and others illness experiences, with consideration given to the individual's sense of self, their body, the illness and their expectations for the future. Frank, in his book *The Wounded Storyteller* (1995), republished in 2013, presents ill people as wounded storytellers, taking the view that

*"Whether ill people want to tell stories or not, illness calls for stories."* (Frank, 1995, p. 54)

The need to tell stories about one's illness can arise from the ill person losing a sense of where they are in life or where they may be going, as well as from others looking for information about what is going on (Frank, 1995; 2013). Frank, identifies three different storylines; which he proposes are present 'alternatively' and 'repeatedly' in the telling of any illness story or narrative (Frank, 1995). These are the restitution narrative, the chaos narrative and the quest narrative, outlined in Table 3.

**Table 3: Basic illness narrative storylines, adapted from Frank (1995)**

Illness narrative	Characteristics
Restitution narrative	<p>Movement from being healthy, to being sick, then returning to health.</p> <p>Illness temporary and curable, body requires treatment, person remains the same, future not disrupted by illness.</p>
Chaos narrative	<p>Life will never get better, told in the present, no sequence of events.</p> <p>Illness severe and irreversible, body has no control, person overwhelmed, future unpredictable</p>
Quest narrative	<p>Accepting the illness and using the experience of that illness for a purpose.</p> <p>Illness is a journey, person has changed, interruption to life and self is viewed as a challenge</p>

While diaries have previously been explored using a narrative approach (Egerod & Christensen, 2009), this PhD research is focused on nurses, patients and family member experiences with diaries rather than the diary itself, which contains several different stories as part of the main illness story (Roulin, et al., 2007).

Hydén and Brockmeier (2008) state that

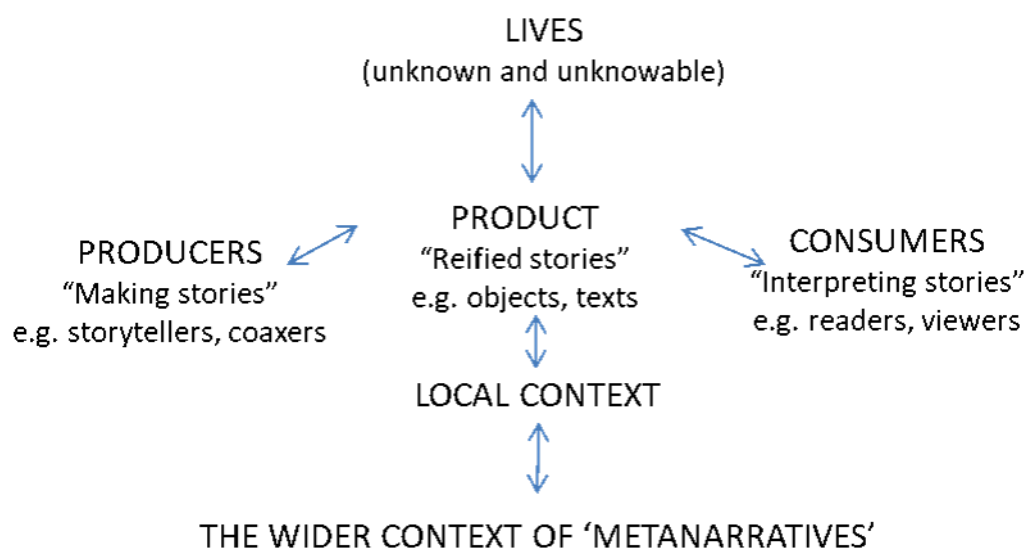
*“Illness narratives offer a unique window on how a disease, a disability, or a trauma is lived by feeling and suffering human beings, with all its consequences for their mental, physical, and everyday life.” (p. 3)*

Due to the nature of critical illness, patients are often unable to talk or write about their experience at the time, yet examples do exist in the literature (Rier, 2000), however this is uncommon. In the wider context of recovery from critical illness, the

critical care diary is incomplete as an illness narrative, as it does not originate from the individual experiencing the illness, and to make sense of this experience, patients need to construct their own illness narrative. For example, as found by Egerod et al (2011b) diaries were used by patients alongside other sources, including family members, to construct their illness narratives. Therefore, although diaries share some features with illness narratives it is important to consider the process of storying in relation to illness experiences and the diary. Furthermore, people's experiences of diaries, as demonstrated by Egerod et al (2011b), are related to how they use the diary.

### 2.8.2 Storying and the experience of illness

People make sense of their experiences and construct reality through the process of storying, or creating a narrative (Bruner, 1986). People's life stories are created through joint actions, as demonstrated in Figure 3.



*Figure 3: Life Stories as Joint Actions (Plummer, 1990, p. 137)*



Plummer (1990) developed this concept from the theoretical perspective of Symbolic Interactionism, recognising that story telling processes emerge through joint actions.

*“No life story can ever be told in a social vacuum: they emerge in joint actions, are organised through joint actions, become objects for interpretation in joint actions, and can be refashioned through joint actions.” (Plummer, 1990, p. 136)*

Illness, whether chronic or acute, is viewed as a disruptive event in an individuals' biography or life story (Bury, 1982; Ramsay, 2010). For patients recovering from critical illness, this disruption is most significant in the early stages of recovery at home following discharge from hospital (Ramsay, 2010). Patients recovering from critical illness express not knowing what happened to them or what caused this to happen, with lost time and a lack of information contributing to this disruption (Ramsay, 2010).

The process of reconstructing one's biography or life story is

*“...an attempt to reconstitute and repair ruptures between body, self, and world by linking-up and interpreting different aspects of biography in order to realign present and past and self with society. (Williams, 1984, p. 197)*

Furthermore, and as demonstrated in the concept of 'Life Stories as Joint Actions' (Plummer, 1990), the suffering associated with illness results in the person experiencing the illness reaching out to others (consumers) to tell their story (Hydén & Brockmeier, 2008). To begin with this may include a family member or a friend, however if the illness and suffering continues healthcare professionals may need to be involved (Hydén & Brockmeier, 2008). Charon (2006) notes that the process of healing begins through telling stories about the illness and suffering. Therefore, storying is an important aspect of the experience of illness.

As identified earlier in the literature review, research exploring experiences with critical care diaries has mainly focused on patients and how they use the diary during their recovery, see section 2.6. The diary can help to fill in the lost time and it is recognised that for patients, whether they are given a diary or not, constructing a story can help them recover from the psychological impact of intensive care and

critical illness (Williams, 2009; Williams, 2010). However, families too can experience disruption in their lives, relating to critical illness and it is unclear at present what role the diary may play for family members who are actively involved in storying or writing about the critical illness experience.

With regards to family members and critical care diaries, extensive research undertaken by James Pennebaker has demonstrated that storying through the process of expressive writing can help people cope with emotions experienced from traumatic events, as well as offering health benefits to those coping with stress (Pennebaker & Beall, 1986; Pennebaker, 1993; Pennebaker, 2000; Pennebaker & Chung, 2011). Expressive writing involves the individual writing about emotional experiences, however unlike diary writing this writing is generally not shared with other people (Pennebaker, 2000; Pennebaker & Evans, 2014). Furthermore, the work around expressive writing does not help us to understand or explain experiences of diaries relating to patients reading the diary or nurses writing in the diary.

Critical illness is a shared experience and the stories written about this experience are created and read by multiple people including the patient, their family members and the nurses looking after them. The need to explore diaries from multiple experiences and perspectives is supported by the view that storying is a joint action. Through storying or creating a narrative people can make sense of their experiences, whether that is through reconstruction of the life story or through the process of writing about emotions.

## **2.9 Chapter summary**

This chapter has introduced the reader to the area of critical care diaries, setting the scene in the context of supporting patients and family members with the experience of critical illness. An overview of the origin and incidence of diaries revealed that critical care diaries are a nursing intervention introduced in Scandinavia in the 1980's and since then have continued to spread worldwide, which has led to variation in how this intervention is currently delivered. Current practice relating to the patient group, authorship, content including the use of photographs, handover and

nursing input in maintaining and establishing diaries in practice, further highlights this variation.

Research in this area has mainly focused on the use of diaries for patients during their recovery from critical illness, yet as noted in the literature, family members and nurses co-create the diary during the time in ICU. The two main areas of research discussed in this literature review focus on evaluating the effect of diaries on recovery from critical illness and experiences with critical care diaries. Research relating to the effect of diaries supports their use as a therapeutic intervention for psychological and emotional wellbeing in patients, and more recently family members, during recovery from critical illness. However, there are several limitations and further research is required. Research on the experiences of diaries focuses mainly on patients using the diary during their recovery. This has given some insight into what it is like for the patient to receive and read their diary, with one of the main findings being that the diary can help patients understand and come to terms with the experience of critical illness. However, there is a lack of research and knowledge around experiences of diaries, especially from family members and nurses who as noted are the main users of the diary during the time in ICU.

Finally, having identified the main gaps in the literature leading to experiences of diaries as an area requiring further research, consideration was given to how critical care diaries and experiences of critical care diaries could be conceptualised. The areas of illness narratives and storying were introduced in relation to the experience of illness and studying experiences of critical care diaries. The concept of storying as a joint action was introduced, supporting the need to explore diaries from multiple experiences and perspectives. Further discussion on theoretical perspectives influencing the design of this research will be outlined in the following chapter on Research Design and Methods.

## Chapter 3 Research Design and Methods

### 3.1 Introduction

This chapter provides a detailed account of the research design and methods used to conduct the research study. The overall research aim and questions are presented, followed by an introduction to the appropriateness of qualitative research. A section on research design introduces the reader to the ontology, epistemology, theoretical perspective and methodology on which the research is based. The methods are outlined following this and the chapter concludes with discussion around ethical considerations and trustworthiness of the study.

### 3.2 Research aim and questions

The overall aim of this research study is:

- To gain an understanding of the perspectives and experiences of patient's, nurse's and family member's use of critical care diaries.

To meet this aim, three main research questions were developed. These are:

- What is the patient experience of having a diary?
- What is the nurse experience of using a diary?
- What is the family member experience of using a diary?

The generic nature of the research questions relates to the theoretical underpinning (symbolic interactionism) and methodology (focused ethnography), as outlined in sections 3.4.3 and 3.4.4, by acknowledging that different groups of people interact with and experience critical care diaries. Therefore, the overall aim is the main focus of this study.

The overall research aim and questions informed the research design and methods used which will now be outlined in detail.

### 3.3 Qualitative Research

A qualitative approach was selected for the research study based on the research aim and questions which were created with the primary aim to explore people's

experiences of critical care diaries. Qualitative research aims to explore, understand and describe participants' experiences through an inductive approach (Holloway & Wheeler, 2010), generating new knowledge and theory grounded in human experience (Bryman, 2008).

*“Researchers engaging in a qualitative study focus on observing, describing, interpreting, and analysing the way that people experience, act on, or think about themselves and the world around them.” (Bazeley, 2013, p. 4)*

Thus, people are studied in a natural environment or setting with attempts made to interpret or make sense of phenomena from the meanings people bring (Denzin & Lincoln, 1998). This holistic approach therefore lends itself to exploring complex phenomena such as experiences of critical care diaries, by taking account of the context in which diaries are created and used as well as valuing the importance of people's experiences with diaries.

### **3.4 Research Design**

Crotty (1998) identifies four basic elements that should be considered in developing any research proposal. These are epistemology (linked with ontology), theoretical perspective, methodology and methods. Each element is interconnected, informing one another and the research design (Crotty, 1998). In the process of designing this research, the research aim and questions were developed first and from these a qualitative approach to inquiry was selected. Prior to making a final decision on the ontological and epistemological stance underpinning the research a theoretical perspective was identified. However, the order in which this is presented will follow the relationship these elements have with each other rather than the order in which decisions were made by the researcher. Therefore, the following sub-sections will start by outlining the ontology and epistemology, followed by the theoretical perspective and methodology informing the research design and at the end an overview of alternative qualitative approaches considered. Methods will be dealt with separately in section 3.5 as there are many different aspects requiring discussion.

### 3.4.1 Ontology

Ontology has been defined as

*“...the study of being...” (Crotty, 1998, p. 10)*

It is concerned with ‘what is’, in terms of the nature of reality and the nature of existence or being (Crotty, 1998). This research is situated within a relativist ontological position where realities are said to

*“...exist in the form of multiple mental constructions, socially and experientially based, local and specific, dependent for their form and content on the persons who hold them (Guba, 1990, p. 27).*

With regards to persons, Guba and Lincoln (1994) note this can be individual persons or groups. Therefore, a relativist ontology, through acknowledging the existence of multiple realities constructed in people’s minds, supports the decision to explore and understand the experiences of critical care diaries from multiple individual and group perspectives.

### 3.4.2 Epistemology

Epistemology is the theory of knowledge, dealing with

*‘...how we know what we know.’ (Crotty, 1998, p. 8)*

It is concerned with what kinds of knowledge are possible and how acceptable or authentic this knowledge is (Crotty, 1998; Holloway & Wheeler, 2010).

The epistemological stance supporting this research is constructivism. However, to begin with the researcher incorrectly linked constructivism with ‘social’ constructionism, believing that they were the same and using both terms interchangeably until realising that they are quite distinct from one another. Appleton and King (1997) highlight this common error and acknowledge the confusion it can cause for researchers. Additionally, they note the difficulty researchers have, whether experienced or not, from the absence of a clear definition for the term constructivism (Appleton & King, 1997). Constructionism however has been defined as

*“...the view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context.” (Crotty, 1998, p. 42)*

In contrast, knowledge and meaningful reality in constructivism exist and are created or constructed with the individual mind. Therefore, it is the way in which knowledge and understanding are constructed that helps differentiate constructivism from constructionism. However, a common thread running through both constructivism and constructionism is that knowledge and meaning is not found or discovered, it is constructed.

Schwandt (1994) notes that humans

*“...invent concepts, models and schemes to make sense of experience...we continually test and modify these constructions in light of new experience.” (pp. 125 - 126)*

Therefore, meaning can change through time with new interactions and experiences. Furthermore, it is possible for multiple knowledges to coexist, leading to a range of views emerging (Guba & Lincoln, 1994).

The researcher had to be clear in her mind that the focus of this research was not on critical care diaries but about exploring the phenomenon of people's experiences with critical care diaries, thus informing our understanding of diaries through learning about experiences. Therefore, diaries can be seen to be socially constructed, created in the ICU by nurses and family members. The reality of people's experiences exists within the individual person or group, which is why a relativist ontological position was taken to acknowledge the multiple, constructed and holistic realities that may exist (Lincoln & Guba, 1985). However, in the epistemological stance of constructivism the only way to access these multiple views of reality is through interaction between the researcher and research participants throughout the research process (Appleton & King, 1997). Guba and Lincoln (1989) therefore assert that taking a constructivist stance eliminates the distinction between ontology and epistemology as one cannot be considered without the other.

### 3.4.3 Theoretical perspective

The philosophical position informing the methodology is known as the theoretical perspective and it is within this perspective that assumptions rooted deep within the methodology are uncovered (Crotty, 1998).

*“Different ways of viewing the world shape different ways of researching the world.” (Crotty, 1998, p. 66)*

Therefore, it is essential that the researcher understands and can explain the theoretical perspective informing their research.

#### Interpretivism

The theoretical perspective informing this study is interpretivism which is concerned with human beings and the way in which they make sense of and interpret their reality (Holloway & Wheeler, 2010). Interpretivism is linked with the concept of ‘Verstehen’ which means to understand something in its context. Furthermore, it is associated with the thoughts of Max Weber who believed that in the social sciences, understanding is fundamentally different from explanation, accepted in the natural sciences (Holloway & Wheeler, 2010).

The overall aim of the study fits in with interpretivism through which an understanding of the experiences and perspectives of patient’s, nurse’s and family member’s use of critical care diaries can be explored from within the reality of their world so, for example, how they make sense of and attach meaning to their experiences with diaries.

#### Symbolic interactionism

The specific strand of interpretivism adopted is Symbolic Interactionism. Symbolic Interactionism (SI) is a theoretical perspective that can be used for qualitative, quantitative and mixed methods research in nursing, with the potential to expand understanding of human health behaviours (Benzies & Allen, 2001). SI is grounded in the social sciences and George Herbert Mead, one of the founding scholars, is regarded as having the greatest influence on this perspective within sociology (Reynolds, 2003). The term ‘symbolic interactionism’ was created by one of Mead’s students Herbert Blumer in 1937 and since then has been used to describe



*“...a relatively distinctive approach to the study of human group life and human conduct...” (Blumer, 1969, p. 1).*

SI was developed further by Blumer into a theoretical perspective through the interpretation, synthesis and publication of Mead’s work following his death (Benzies & Allen, 2001). Additionally, Blumer developed his own version of SI (Blumer, 1969), otherwise known as Chicago-style, Blumerian or Traditional SI (Serpe & Stryker, 2011), and the version used to inform this research.

Alongside Chicago-style SI is the Iowa school otherwise referred to as Social Structural SI (Serpe & Stryker, 2011), which together represent the two most well-known and contrasting approaches of SI (Benzies & Allen, 2001; Meltzer, et al., 1975). Major differences between the two schools of thought (and others) are outlined by Prus (1996) who suggests that these differences originate from the ways

*“...one might study human group life...” (p. 77).*

For example, Manford Kuhn who developed the Iowa school, was interested in creating an objective testable theory of human behaviour,

*“...a theory of self and interaction...” (Prus, 1996, p. 76).*

Thus, the Iowa school is associated with positivism. Whereas Blumer recognised the importance of studying the empirical social world through human lived experience (Blumer, 1969), resulting in a more humanistic approach. However, in common with all variations of SI there is a fundamental belief that reality is constructed by human beings through a process of interaction with other human beings. Therefore, to understand reality as another person does one must try to get inside that person’s reality (Meltzer, et al., 1975). The main differences in approaches lie in the methods used to generate knowledge and how key concepts underpinning SI for example ‘the self’ are viewed (Burbank & Martins, 2009).

Table 4, adapted from Serpe and Stryker (2011, p. 230) highlights further the main differences between the two perspectives:

**Table 4: Traditional and Structural Symbolic Interactionism comparisons, adapted from Serpe and Stryker (2011, p. 230).**

<b>Traditional Symbolic Interactionism (Chicago)</b>	<b>Structural Symbolic Interactionism (Iowa)</b>
Self and social organisation inconsistent, social life unpredictable. Testing theories of social psychological phenomena not possible. Interaction described as it occurs and understanding happens after interaction occurs.	Social life consistent. Possible to seek empirical generalisations beyond individual interactions. Concepts applied to different situations to aid understanding.
Definitions and individual interpretations change continuously in interactive situations, extending to social life. Interaction described as it unfolds, application of concepts representing social structure or prior analysis of interaction questionable.	Social structure included when studying social psychological processes. Social structure considered as stable patterns of social relationships and social interaction which constrains definitions and individual interpretations. Therefore, allowing the use of structural concepts in analyses.
Only perspectives of participants in social interaction are relevant to understanding their interaction.	Perspectives of participants in social interaction must be considered however are insufficient as explanations of behaviour.
Self emerges from society, free of structural constraints over time and an independent source of social behaviour.  Novelty and creativity highly probable in social life. Social life continuously newly constructed.	Self, a channel for prior social organisation and structure to reproduce.  Novelty and creativity possible but limited by social life reproducing existing patterns.
Qualitative research methods - ethnography, participant observation, intensive unstructured interviewing.	Social science data gathering methods - sample surveys, simulations and experimentation and quantitative methods of data analysis.

Symbolic interactionism is based on three fundamental principles:

- 1. human beings act towards things on the basis of the meanings that the things have for them.*
- 2. the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows.*
- 3. these meanings are handled in, and modified through, an interpretive process used by the person in the things he encounters.*

*(Blumer, 1969, p. 2)*

The fundamental principles described by Blumer are common to the different variations of SI (Meltzer, et al., 1975). However, as this research is informed by Chicago-style SI the principles will be discussed from this viewpoint. Furthermore, it is important to note that the term 'things', used throughout the fundamental principles of SI, can be taken to mean physical objects, other human beings, categories of human beings, institutions, guiding principles, other people's activities and situations encountered in one's daily life (Blumer, 1969, p. 2).

The first principle indicates that people do not just act towards things, they attach meaning to those things and act based on the meaning rather than the thing. The second principle is concerned with the source of the meaning and as described originates from a process of interaction between individuals in relation to the thing. Blumer believes that this sets SI aside from other views as it does not view meaning as originating from

*"...the intrinsic makeup of the thing..." or as an expression of  
"...psychological elements in the person..." but from "...the ways in  
which other persons act toward the person with regard to the thing..."*  
*(Blumer, 1969, p. 4).*

The third principle refers to the process of interpretation, used by the person in encountering things. This process has two separate stages that involve self-interaction or communication with oneself. Firstly, the person 'indicates' to himself the thing he has encountered i.e. the thing he is acting towards, the thing that has meaning. Secondly, the person manages meanings associated with the thing in the

context of the current situation, which then guide action (Blumer, 1969, p. 5). Thus, meanings are constructed and modified through the interaction an individual has with one's self and others in any given situation or encounter (Burbank & Martins, 2009).

### **Symbolic Interactionism and experiences of critical care diaries**

The perspective of Symbolic Interactionism (SI) has been influential from an early stage in developing and informing the research design. When SI is used as a 'lens' in qualitative health sciences research it is possible to uncover multiple meanings and understandings, co-constructed in the context of the social world as the researcher will remain open to the

*"...relevant social context within which individual subjective experience is shaped..." (Handberg, et al., 2015, p. 1026)*

Furthermore, Blumer identifies several basic concepts he refers to as 'root images' that collectively represent how

*"...symbolic interactionism views human society and conduct..." (Blumer, 1969, p. 6).*

One of the root images Blumer identifies is particularly relevant to this research and this is the nature of objects. Objects are classified into three categories: physical objects; social objects; and abstract objects. Blumer states:

*"The nature of an object – of any and every object – consists of the meaning that it has for the person for whom it is an object. This meaning sets the way in which he sees the object, the way in which he is prepared to act toward it, and the way in which he is ready to talk about it. An object may have a different meaning for different individuals..." (Blumer, 1969, p. 10)*

The critical care diary is primarily a physical object, a note book used to record information for the patient during the time they are in the intensive care unit (ICU). It is an object for nurses, family members and patients, who access it at different times throughout the critical illness journey (or during and after ICU). From a SI perspective, it is acknowledged that the diary may have different meanings for different people. Therefore, how individuals use diaries will depend on what meaning the diary has for them. Exploring the meaning diaries have for the different

groups using them and their experiences may help us to understand further the way in which diaries are used and perceived or experienced by these individuals.

Until recently, and as discussed in the literature review chapter, research on diaries has mainly focused on the diary being used by the patient and their family during recovery from critical illness. However, the diary is co-created or written in the intensive care unit (ICU) by nurses and family members at the patient's bedside. Therefore, this research aims to explore the use of critical care diaries through an understanding of the experiences and perspectives of patients, nurses and family members and the theoretical perspective of SI supports this.

### **3.4.4 Methodology**

Methodology has been described by Crotty (1998) as a strategy or plan of action. The design or approach chosen influences the selection of methods used to meet the outcomes of the research (Crotty, 1998). An ethnographic approach known as focused ethnography was adopted for this research. However, an overview of ethnography and ethnography in healthcare research will be given first as it is from this that focused ethnography evolved. Alternative approaches considered will be discussed following this.

### **Ethnography**

Ethnography is recognised as one of the oldest research approaches, becoming popular in the 19<sup>th</sup> and 20<sup>th</sup> century from cultural anthropologists who were interested in studying small communities and how they lived (Morse & Field, 1996; Holloway & Todres, 2010). Ethnography was influenced further by sociologists and scholars at the University of Chicago, working on the study of human lived experience, including George Herbert Mead whose work on human group life provided the foundation to the theoretical perspective of Symbolic Interactionism (Prus, 1996), outlined in section 3.4.3. Hammersley and Atkinson (2007) discuss how ethnography has continued to develop throughout the 20<sup>th</sup> and 21<sup>st</sup> century, spreading across different disciplines and countries, resulting in there being no single standard definition of ethnography. Lambart et al (2011) comment that it is often easier to describe what ethnographers do rather than define ethnography. Whereas Savage (2000; 2006) has argued that this lack of definition has played a part in

ethnography being under-utilised in healthcare research. However, this argument appears to be outdated, at least in critical care, with several examples of ethnographic research being conducted in the past few years (Kydonaki, et al., 2014; Reeves, et al., 2015; Van Keer, et al., 2015; Dale, et al., 2016; Hales, et al., 2016).

The term ethnography can relate to the methods, a methodology, the written account or a combination of all three (Savage, 2006). In this thesis, the term ethnography is used to represent the methodology, which has influenced the selected methods, as will be demonstrated in section 3.5. The main methods used in ethnography include participant observation, interviews and the examination of available documents (Roper & Shapira, 2000). Boyle (1994) recognises that there are different types of ethnographic approaches, however they all share common characteristics in that they are holistic and contextual, reflexive, use emic and etic data and produce a final account or ethnography containing thick description. The type of ethnography chosen will depend on the ‘social unit’ to be studied whereas the final account will depend on the skills and training of the researcher (Boyle, 1994). This includes the researcher’s epistemological stance (Boyle, 1994), which is embedded in the researcher’s view of the world or theoretical perspective (Crotty, 1998).

With regards to this research, it has been noted by Crotty (1998) that an ethnographic approach underpinned with Symbolic Interactionism

*“...seeks to uncover meanings and perceptions on the part of the people participating in the research, viewing these understandings against the backdrop of the people’s overall worldview or ‘culture’.” (p. 7)*

Therefore, researchers endeavour to understand phenomena from the perspectives of participants (Crotty, 1998), otherwise known as the emic perspective or insider’s view. This is in keeping with the overall aim of the research, to gain an understanding of the perspectives and experiences of patients, nurses and family members use of critical care diaries.

Morse and Field (1996) suggest that:

*“Ethnography is a means of gaining access to the health beliefs and practices of a culture and allows the observer to view phenomena in the*

*context in which it occurs, thus facilitating our understanding of health and illness behaviour.” (p. 21)*

Most research on critical care diaries has implemented diary use as part of the research protocol whereas this research aims to gain an understanding of people's experiences of diaries in the context of how they are used in practice, in a Scottish ICU. One of the main reasons for this is that at the time of designing the research very few units in Scotland were using diaries and no research had been conducted in Scotland in this area. Therefore, taking into consideration the context in which diaries are created was important.

In nursing, it has been suggested that ethnography is not just about generating knowledge but about trying to improve and change practice through an understanding of the context in which this takes place (Holloway and Todres, 2010). Therefore, using an ethnographic approach not only provides insight into practice from the experiences of patients, families and nurses in NHS Scotland but allows us to consider if and how this nursing intervention could be used in Scottish ICUs. However, as asserted by Hammersley and Atkinson (2007) ethnography can involve spending a prolonged time participating in people's daily lives observing what is going on, listening to what is being said and asking questions about this, as well as collecting other available information in a physical format such as documents. A traditional ethnographic approach was therefore not suitable for this research as it was not possible or appropriate to observe experiences of diaries through participating in people's daily lives over a prolonged time.

The context in which the diary is experienced is different for patients, family members and nurses. For example, the diary is created in the ICU by nurses and family members however, due to the patient's illness and treatment they are unlikely to be aware of the diary at this stage. Therefore, another concern in adopting an ethnographic approach was that the patient's voice would be lost. Despite these initial concerns with ethnography, this approach was reconsidered after exploring the suitability of other qualitative approaches, reported in section 3.4.4, and after learning about a type of ethnography used in nursing research known as focused ethnography (Morse & Field, 1996; Roper & Shapira, 2000).

### **Focused ethnography**

Focused ethnography was selected as the methodology informing this research. This type of ethnography is topic orientated (Morse, 1989), meaning that researchers select a topic for investigation prior to collecting data (Morse & Field, 1996).

Focused ethnographies normally deal with distinct problems in specific contexts (Wall, 2015) and research questions relate to the experiences of groups or sub groups within specific cultural contexts (Higginbottom, et al., 2013). Therefore, focused ethnography can be applied

*“...to any discipline whenever there is a desire to explore specific cultural perspectives held by sub-groups of people within a context-specific and problem-focused framework.” (Higginbottom, et al., 2013, p. 1)*

Recognised as a qualitative research approach in the health sciences, Muecke (1994) provides a useful overview of the differences between some of the more traditional ethnographic approaches and focused ethnography. Key characteristics of focused ethnography include: focusing on discrete communities or organisations; selecting episodes of participant observation; unstructured and semi-structured interviews; and limited numbers of participants who have been selected for their knowledge and experience of the phenomenon rather than those with whom the researcher, over time, has developed a close, trusting relationship (Muecke, 1994). Additionally, Cruz and Higginbottom (2013) note that individuals with knowledge and experience of the phenomenon being studied may not live in the same area and therefore the need to engage in prolonged fieldwork, for example through participating in people's daily lives (Hammersley & Atkinson, 2007), is not necessary. Intensive data collection, using audiovisual recording techniques is common and compensates for short-term field visits by producing a large amount of data for analysis (Knoblauch, 2005). However, it can be difficult to do this without some background knowledge or familiarity with the setting (Knoblauch, 2005). Therefore, it is important for the researcher to establish rapport and become familiar with the setting, including the practices and language used (Morse & Field, 1996).

Roper and Shapira (2000) have identified three different areas in nursing research where focused ethnography has been applied. These include the study of how health



practices and beliefs have been integrated into people's lives in different cultures, understanding meanings that members from subcultural groups assign to their experiences and exploring nursing practice as a cultural phenomenon. Therefore, the main purpose of this research approach in nursing, in addition to improving and changing practice, is to gain further insight and understanding into shared experiences and phenomena of interest to nursing (Cruz & Higginbottom, 2013).

In summary, the main reason behind selecting focused ethnography is that it allows the researcher to focus specifically on the experiences of critical care diaries. Key to the approach taken in this research is that patients, nurses and family members are brought together through the experience of critical illness. Without the experience of critical illness, and a stay in the ICU, there would be no diary. Therefore, it is important to explore experiences of critical care diaries within this context and from the different groups of patients, nurses and family members. Focused ethnography acknowledges the different groups involved and shared experiences. Furthermore, although the researcher was already familiar with an ICU setting, she did not have experience working in an ICU with critical care diaries. Therefore, selecting an ethnographic approach such as focused ethnography allows the researcher to gain further insight into the ICU setting where the practice of critical care diaries occurs, which may help further in understanding peoples experiences.

### **Alternative qualitative approaches considered**

There are various qualitative approaches to choose from and a significant amount of time was spent exploring different approaches before finally deciding on focused ethnography. In addition to ethnography and focused ethnography, the two other main approaches considered were phenomenology and grounded theory method.

Phenomenology was one of the first approaches considered, as the researcher associated phenomenology with exploring people's experiences. Phenomenology aims to gain knowledge and insight about a phenomenon through uncovering, describing and interpreting everyday experiences known as the 'lifeworld' or 'lived experience' (Holloway & Wheeler, 2010). Experience is accepted as it is, in the consciousness of the individual (Morse & Field, 1996).

There are three main types of phenomenology: descriptive (Husserl), interpretive or hermeneutic (Heidegger) and existentialist (Merleau-Ponty) however the two most common types of phenomenology used in nursing research are descriptive and interpretive phenomenology (Todres & Holloway, 2010). The main difference between descriptive and interpretive phenomenology is around what to do with preconceptions held by the researcher about the phenomenon being studied (Todres & Holloway, 2010).

Phenomenology is concerned with describing and understanding the world of the individual in relation to an experience or phenomenon. Whereas this research is concerned with understanding experiences and perspectives from different but overlapping worlds. An interest in the interaction between different worlds and individuals, in relation to the experiences of critical care diaries, as well as the context in which these experiences are formed therefore means that this research is not just concerned with the lived experience. However, if only one group and their experiences with diaries were being studied, then phenomenology as an approach to qualitative research may have been selected. Research on diaries published after designing this study have used this approach (Périer, et al., 2013; Johansson, et al., 2015).

Furthermore, as will be discussed later in this chapter, the researcher was keen to carry out observations of nurses performing diary related activities to inform her understanding of this practice and provide context for people's experiences, see section 3.5.5. The use of observation as a method of collecting data is generally not supported within a phenomenological approach, as the lifeworld can only be accessed from the individual who has lived that experience, whereas observation is from the perspective of the researcher (Holloway & Wheeler, 2010).

Grounded theory, the second alternative qualitative approach to be discussed, is concerned with

*"...the discovery of theory from data systematically obtained from social research..." (Glaser & Strauss, 1967, p. 2).*

Grounded theory is quite distinct from other approaches as it is a collection of methods rather than an approach. The evolution of grounded theory method over the last few decades has seen it develop in different directions. However, there are three main features present in all grounded theory methods that continue to differentiate it from other methods. These are (i) theoretical sampling, (ii) constant comparative analysis and (iii) development of theory (Hood, 2007). Grounded theory offers a systematic method to collect and analyse data, with the purpose being to generate theory. Theory emerging from data can help us understand and explain the social and psychological processes that are responsible for any interaction or variation surrounding a phenomenon (Chenitz & Swanson, 1986). For example, Egerod et al (2011) used grounded theory method to explore how patients and family members used diaries in the context of the illness trajectory. Findings demonstrated that the diary was a source of information used in ‘constructing the illness narrative’ which was part of the psychosocial process of recovery after critical illness (emerging theory).

Grounded theory method was given considerable thought as it had roots in the theoretical perspective of symbolic interactionism and allowed simultaneous data collection and analysis. However, as discovered from further reading, these features were not exclusive to grounded theory method, for example simultaneous data collection and analysis have been reported as a common activity for qualitative researchers (Holloway & Wheeler, 2010). Nevertheless, grounded theory can be useful in areas where there is little existing research, for example as demonstrated by Egerod et al (2011b).

The main reservations with grounded theory method at the time of designing the research were around how practical it would be. Sampling was an issue as it was planned that patients, nurses and family members would be recruited as a triad, see section 3.5.4. The researcher was unsure how theoretical sampling would work with triads with the main concern being that each triad would need to be complete before moving onto the next, which would have been time consuming. Furthermore, there would be a delay with patient interviews, as patients would be interviewed later in their recovery which may have also affected the constant comparative process of

collecting and analysing data. From reviewing the literature, it became apparent that patients, nurses and family members may use the diary in different ways at different times which is why the researcher wanted to explore experiences from all three groups. However, this might have led to the emergence of several different theories. Finally, the overall aim of the research was not to generate a substantive theory to represent and explain processes relating to the experiences and perspectives of the use of critical care diaries. The overall aim was to gain an understanding through exploring differences and similarities within and across the groups of nurses, patients and family members.

### **3.5 Methods**

As outlined in the previous section on research design, section 3.4, there were many decisions to make in developing this research. The different methods involved in conducting this research will now be addressed including: selecting and gaining access to the research site; sampling; data collection techniques; data management; and data analysis. The researcher will outline in detail each step taken and the decisions made throughout the research process in implementing these methods.

#### **3.5.1 Selecting the setting**

The process of identifying and selecting the unit started in January 2012. The researcher contacted all adult critical care units in NHS Scotland with level 3 beds. Units were identified using ICU profile data obtained from the Scottish Intensive Care Society Audit Group (2011) annual report. A total of 23 units were identified and contacted by telephone to find out if they were using diaries or not. At least one nurse from each unit was spoken to and most of them had an awareness of diaries. It was determined that six units had experience with diaries. There were only three nurses, each from different units, who did not know anything about diaries.

The focus on gaining an understanding of the experiences and perspectives of those who write in and read the diary made it essential for the research to be conducted in a unit where diaries were currently being used so that participants could give an account of their experiences. However, on further questioning of the six identified units who claimed to have experience with diaries, only one unit was established in

using diaries on a regular basis. This was as part of a follow up service, similar to what has been described in the literature and other areas of the UK. The researcher chose to exclude the remaining five units based on not being able to recruit suitable participants i.e. those who had been given the opportunity to use a diary.

Additionally, it was important to complete recruitment and data collection within the planned time frame of 18 months. The risk of the diary intervention being discontinued in units where it was not fully established or had previously been stopped was higher than in the unit where diaries were established and embedded within practice. Therefore, the one unit established in using diaries on a regular basis was selected.

The setting for the study was an acute NHS hospital in central Scotland. The critical care unit was a combined unit with 5 general level 3 ICU beds and 7 surgical level 2 HDU beds. The ICU population comprised of a mix of medical and surgical patients, including elective and emergency admissions.

### **3.5.2 Gaining access**

Gelling (2010) recommends approaching and negotiating access with ‘gatekeepers’ as early as possible in the planning stages of a research project. This is important as it can enable the researcher to develop a rapport as well as receive feedback on the proposed research, thus allowing time for changes to be made prior to submission for formal approvals. The process of gaining access to the research site was initiated a year prior to the study starting. From this initial contact the Charge Nurse responsible for introducing diaries was identified.

Hammersley and Atkinson (2007) advise that once the type of research setting has been decided on, the researcher should try to ‘case’ potential sites. Having identified who to contact, a second phone call was made and the researcher was invited to visit the unit in February 2012. This was an informal visit where the researcher met with the Charge Nurse, who explained the follow up service provided for patients and family members as well as the diaries they used. The proposed research was discussed which was met with enthusiasm and interest from the Charge Nurse who offered her support. The researcher then met the staff on duty and had a quick look

around. The process of ‘casing the joint’ as described by Hammersley and Atkinson (2007) provides the researcher with information about the setting, which can help inform decisions around the suitability of the site, including the feasibility of being able to conduct the research there and how to establish access.

Following the site selection visit, contact was maintained via email with the Charge Nurse. However, it was important to establish a more formal agreement with the site. The main concern, having learnt that this was the only unit in Scotland established in using diaries on a regular basis, was that someone else with a similar interest may wish to carry out diary research in this setting. The key gatekeepers identified from the initial visit were the Clinical Director and Senior Charge Nurse who were contacted in writing in May 2012. The study was still being developed at the time and therefore a short summary was created and sent (see Appendix 1). It was agreed with the Clinical Director that a copy of the protocol would follow, prior to NHS Research Ethics Committee (REC) review. Formal permission to access the unit for the research was provisionally agreed in writing, pending all the necessary approvals being in place and support from the nursing team.

The local NHS Research and Development (R&D) department for the research site was contacted in July 2012 to determine the process for R&D management approval and sponsorship. It was determined that sponsorship should be provided from the university where the PhD was undertaken. Furthermore, it was highlighted that the researcher would require a Letter of Access to be in place granting her formal permission as an NHS employee to conduct research in a different NHS Health Board to her own. The main contact for the site, during the run up to NHS REC review in November 2012, was the Senior Charge Nurse who acted as the named Local Collaborator on the advice of the local R&D department. A favourable ethical opinion was granted in December 2012 pending R&D management approval and on the 10th of January 2013 all approvals were in place. The ethical committee review and approval process for this research is described in further detail later in the chapter, see section 3.6.

The first research visit to the site, on the 17th of January 2013, involved meeting with the Charge Nurse and Senior Charge Nurse to discuss the study starting.

Information for nursing staff was to be sent in an email containing a covering letter (see Appendix 2) and Participant Information Sheet (PIS) on the observational aspect of the study (see Appendix 3), which will be discussed later. This decision was based on previous experience of how information was disseminated in the researcher's own unit. However, the Senior Charge Nurse advised against this as not all nursing staff were familiar with and used the NHS email system. It was suggested that it would be more appropriate to print out individual copies of the approved letter and PIS as well as the generic information sheet (see Appendix 4), designed to inform visitors about the study. With around 50 nursing staff working in the unit this was initially time consuming however it worked well as it was possible to monitor who had received the information by placing named envelopes containing the information in a box left in the staff room. Furthermore, by strategically placing the box in the area where staff handed over and went for break, conversation and interest about the study was generated during the early weeks of the study starting.

The researcher was granted 'formal' access at the site with an ID badge which enabled access into the unit without having to wait for a member of staff to answer the secure entry system. This was issued by the hospital security department on the request of the Senior Charge Nurse, who also requested that the researcher added her days onto the nursing rota. On average, visits were twice weekly as the PhD was being undertaken part time. The researcher spent the first few weeks meeting with staff and becoming familiar with the routine and layout of the unit, prior to starting recruitment. It was established at this stage that afternoons were the best time to visit and speak to nursing staff, as this was when lunch break and afternoon visiting happened. Afternoon 'buzz' sessions<sup>1</sup>, lasting around five to ten minutes were conducted at the nursing desk to discuss the study and answer any questions. Once nearly all the nurses had received their information and several 'buzz' sessions had occurred it was agreed with the Senior Charge Nurse that recruitment could begin. Furthermore, the researcher joined staff in the unit for breaks, providing another

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<sup>1</sup> The concept of a 'buzz' session was introduced to the researcher by the Charge Nurse responsible for introducing diaries. This was a local practice used to share information about new initiatives in the unit and nursing staff were familiar with this way of communicating.

opportunity to discuss the study whilst allowing the researcher to get to know everyone and become accepted as a visiting member of staff. Likewise, unit staff used this time to get to know the researcher and ask questions, mainly about the researcher's own unit and hospital.

### **3.5.3 Researcher role and identity**

The researcher had experience in critical care, having worked in an ICU for several years as a staff nurse, surveillance nurse and research nurse. This background experience meant that the researcher was already familiar working in an ICU environment. As noted in section 3.5.1 the unit where the research took place was different from the researcher's own unit. The researcher was open about her ICU experience. However, in her role as nurse researcher, she did not become involved in providing any direct clinical care to patients and their families or participate in any clinical decision making. It was important to maintain this as it was on this basis that ethical approval was given and formal access to the site granted. All nursing staff at the research site were made aware of the researcher's role during the early visits to the site and it was clearly detailed in the information given to staff. Furthermore, it was decided with the charge nurse that the researcher would not wear her NHS uniform or scrubs, to make this distinction in role from staff working in the ICU visible. Furthermore, the researcher kept a reflexive diary (field notes) to document thoughts and feelings throughout all aspects of the research process and any issues in maintaining the role of nurse researcher. In ethnography terms the researcher was an outsider.

### **3.5.4 Sampling**

Sampling is an important aspect of the research process (Holloway & Wheeler, 2010), as it is from sampling that the qualitative researcher will have the opportunity to explore the phenomenon being studied. The decision was made to use a purposive sampling strategy, thus allowing the researcher to obtain rich data. This would help to answer the research questions by including those participants who have personal knowledge and experience of the phenomenon under study (Endacott & Botti, 2005). When using this strategy, participants are selected with predetermined criteria, informed by the research aim and questions. Holloway and Wheeler (2010) note that



purposive sampling can include selection of the research site or setting. For example, as discussed in section 3.5.1 it was important to find a unit where diaries were currently being used to be able to access potential research participants to gain an understanding of their experiences and perspectives on diaries.

As outlined in the study aim the sample population included patients, nurses and family members. Patients recovering from critical illness, nursing staff looking after patients in the ICU and members of the patient's family visiting in the ICU who had been given the opportunity to use a diary, were invited to participate. A decision was made between the researcher and her supervisors to aim to recruit a sample of 15 study participants for individual semi-structured interviews. The sample was to be made up from 5 patients, 5 nurses and 5 family members who were to be recruited in triads. A complete triad consisted of a patient, a member of the patient's family and a nurse who had been involved in caring for the patient during the time in ICU. This approach was in keeping with the overall aim of the research and research questions and to the researcher's knowledge is an approach that has never previously been used in research on critical care diaries.

It was acknowledged at the time of designing the study that the approach of recruiting in triads might need to be modified and this was written into and accounted for in the study protocol as outlined in Figure 4.

- **Data will be gathered from small groups** consisting of a patient, a member of the patient's family and a nurse from the ICU. These are referred to as **triads** and where possible this approach will be taken. However, if any member of a triad withdraws or declines to take part, data from the other members of the triad will be retained and analysed. To ensure sufficient data, recruitment of further members from different groups will occur. So, for example if there are fewer patients in the study than nurses or family members, additional patients will be recruited.

*Figure 4: Data collection and recruitment of triads*

This approach was trialled in the first few months to determine feasibility and the decision was made to continue in this way, having successfully recruited a family member and nurse for a triad in the first month of recruitment.

To ensure adequacy of the study sample, it is useful for the researcher to consider the concept of saturation, which can add to the quality of the research (Endacott & Botti, 2005). However, Endacott and Botti (2007) note that researchers often do not discuss this process in the final research report. The concept of saturation originates from grounded theory method and in this context, it is referred to as ‘theoretical saturation’, whereby no new data emerge to develop ‘categories’ further (Nelson, 2017). The meaning of saturation and how this is achieved is different for different methods (Fusch & Ness, 2015), and several models relating to saturation in qualitative research now exist (Saunders, et al., 2017).

With regards to an ethnographic approach, saturation is achieved through multiple methods of data collection, lengthy time spent in the field and a sample that is representative of the culture (Endacott & Botti, 2007; Fusch & Ness, 2015). Fusch and Ness (2015) note that triangulation, which may include different people and different methods as achieved in this study, can help to ensure saturation.

Furthermore, in this study the researcher sought to obtain rich (quality) and thick (quantity) data, which in combination can strengthen the likelihood of achieving data saturation (Fusch & Ness, 2015). This approach is reflected in the decision to use semi-structured interviews, supplemented with focused observations and reflective field notes, see section 3.5.5. Finally, through the process of thematic analysis, outlined in section 3.5.7, where themes were generated from the interview data, inductive thematic saturation (Saunders, et al., 2017) was achieved. The researcher reached a point in the analysis where no new codes or themes emerged from the data. However, it should be acknowledged that there were limitations in the final study sample, addressed in Chapter 6 of the thesis (see section 6.1.2), which should be taken into account when assessing the extent to which saturation was achieved in this study.

Eligibility criteria specific to each group were used to guide the selection of all research participants for the semi-structured interviews as outlined in Figure 5 on the following page.

On each visit to the site the researcher spoke to the nurse in charge to find out if any new patients had been admitted. Nursing staff kept a diary log book which made it possible to keep track of which patients had a diary started and when and where patients were transferred to. However, on occasion the log book was not always updated. The researcher spoke directly to nurses looking after patients at the bedside to find out who the main family members were and which nursing staff had been looking after them during their stay. From this simple interaction with nursing staff it was noted that nurses often referred to the diary to identify who had been with the patient during their time in ICU.

A range of participants in each group were sought to achieve variety in the sample, for example by gender and age, patient diagnosis and reason for admission to ICU, length of stay, family member relationship to the patient, nursing experience and previous experience of writing a diary for patients in ICU. To allow for flexibility in the selection of participants the researcher obtained permission from the ethics committee to be able to recruit 15 to 20 participants for interviews. While an effort was made to recruit complete triads, as anticipated it was not possible to recruit all participants in this way. A total of four triads and a further two incomplete triads, with missing patients, were recruited giving a total of 16 interviews. Details of the participants recruited for interview can be found in the introductory section to the findings chapter, section 4.1.

## Inclusion criteria

Eligible participants will be:

- $\geq 16$  years of age
- English speaking
- Capable of giving an informed consent

**AND** will meet the specific inclusion criteria for their group as detailed:

- **Patients** recovering from critical illness
  - have had a diary kept for them during their stay in intensive care
  - have been assessed by nursing staff from the unit as ready to receive their diary
- **Nurses** working in the ICU
  - have been involved in diary writing for a patient on at least two shifts
  - are planning to carry out a diary specific activity requiring interaction with a patient or family member e.g. handover of diary to patient (observation activity only)
- **Family members** (up to a maximum of 2 from each family)
  - visiting their relative in the ICU. NB: there is no minimum length of visiting time required to participate in the study
  - have previously been encouraged by nursing staff to write in the diary kept for their relative during this time

## Exclusion criteria

Eligible participants will be excluded if:

- no informed consent has been given to take part in the study
- under the custody of HM Prison service

**OR** they meet one of the specific exclusion criteria for each group as detailed:

- **Patients**
  - ICU clinician refusal to approach patient
  - Admitted with a primary neurological diagnosis
  - Expected to be discharged to another ICU for treatment
  - Discharged to a geographical location out with NHS xxxxx
- **Nurses**
  - Non NHS nursing staff i.e. agency
  - NHS staff from a different ICU
- **Family members**
  - ICU clinician refusal to approach family member(s)
  - With patients who are expected to be discharged to another ICU for treatment
  - Where the decision has been made to withdraw treatment, or provide palliative care for their relative

*Figure 5: Eligibility Criteria*

## Sampling in focused ethnography

*“...includes both individuals in the culture and events which occur within the group that adds to the researcher’s understanding of the values and norms.” (Morse & Field, 1996, p. 127)*

Therefore, in addition to the interviews, focused observations of nurses performing diary related activities took place and examples of diary entries were collected. Sampling for observations was guided by the availability of the researcher and the actual event. For example, one type of event the researcher wanted to observe was nurses handing over the diary to patients in the ward. The sampling of observations was often opportunistic as it was not always possible to predict when such an event may happen. Additionally, various factors had to be taken into consideration such as when the patient would be ready to receive their diary, if there was a member of nursing staff on duty in the diary team who was involved in handing diaries over, what was going on in the ICU and as mentioned the researcher being available to approach for informed consent and observe, whilst continuing to work part time in a different trust. It was anticipated that around 15 to 20 observations would be undertaken by the researcher however challenges with gaining ethical approval to observe in an ICU and hospital setting, outlined in section 3.6.1, impacted on the number of observations performed. A total of 9 diary related events were observed, with four different types of diary related activities included in these, which will be detailed further in section 3.5.5. Fortunately, the main purpose of the observations was to inform the researcher on the practice of diaries in that unit as well as establish trust and build rapport with nurses working there. Thus, the observations although important to begin with became less important and supplemental to the interviews which provided the main source of data.

The researcher selected 38 examples of diary entries from the diaries of the four patients interviewed. Patients assisted in this process by firstly agreeing for the researcher to look at their diary and secondly helping the researcher to identify examples that meant something to them and might be of interest to others who had never seen a diary before. The researcher selected a range of different entries, written at different times throughout the ICU stay by nurses, family members and

friends as well as by the patient themselves in the hospital or at home. The process of selecting diary entries evolved with the process of data collection, which will be discussed further in the following section on data collection techniques.

### **3.5.5 Data collection techniques**

To meet the overall aim and questions of the research study, data were generated mainly through semi-structured interviews which were supplemented with a small number of focused observations of nursing staff carrying out diary related activities, photographs of diary entries and field notes. The following section will give a detailed overview of these methods and how they were implemented.

#### **Semi-structured interviews**

The primary method of data collection was semi-structured interviews which are commonly used in focused ethnography (Higginbottom, et al., 2013), and other qualitative research approaches. Semi-structured interviews, although more structured than an unstructured qualitative interview, offer flexibility which is essential for the researcher to be able to explore unexpected issues raised by participants (Todd, 2010), as well as covering topics listed on the interview guide. Furthermore, with semi-structured interviews the researcher can develop questions and decide what issues to explore (Holloway & Wheeler, 2010).

Interview guides specific to each group were developed to facilitate the interviews (see Appendix 5). These contained a list of approximately eight topic areas to explore, with related questions. The questions were open-ended, and consisted of three different types of questions identified by Rubin and Rubin (2012) as main questions, probes and follow up questions which allow the researcher to achieve depth and detail during the interview. The questions were reviewed prior to recruitment by a former ICU patient and an ICU nurse which was important as it has been suggested that credibility of the researcher can be established through asking questions which are meaningful to participants and demonstrate an understanding of the research subject (Legard, et al., 2003).

The former ICU patient had received a diary following a prolonged stay in the unit and on several occasions after discharge, had returned to help staff by sharing her

experiences. The charge nurse was keen for the researcher to meet this lady and learn about her experiences, including her experience of having a diary. It was agreed that she would help the researcher by reviewing the interview guide and questions created for patients, which were sent in an email prior to the meeting. Whereas for the nurse interviews, the researcher approached a nurse colleague from her own ICU, as she did not want to reveal to nurses at the research site what questions might be asked in case this influenced what they did with diaries or what they might tell her if interviewed. The nurse who reviewed the guide had no experience with diaries however was able to check the wording of the questions, which was very helpful.

It was not possible or deemed appropriate to approach a family member prior to recruitment starting. However, as there had been no major changes made to the patient and nurse interview guides it was decided to proceed with recruitment. Family members were the first participants to be approached and interviewed in each triad therefore it was possible to make and review changes early on. Further minor changes were made to each interview guide as the interviews progressed, informed by responses from participants and other issues arising such as gender and diary use (see the findings chapter section 4.7), which required further investigation.

Holloway and Wheeler (2010) note that the order in which questions are asked and topics covered will not be the same for every interview or participant as this will depend on how the interview develops and what responses are given. The researcher found that participants often moved between different topic areas and some questions were addressed before they had even been asked. However, the interview guides were very useful to keep track of what had been covered and allowed the researcher to listen carefully and focus on what participants were saying, without the worry of forgetting to cover a specific area or ask a certain question.

Furthermore, having an interview guide to refer to ensured that 'similar types of data' were collected from all participants (Holloway & Wheeler, 2010). Although there were three different interview guides used in this study, many topic areas and questions were alike. For example, each guide covered the topic of ways to improve diaries. Distinguishing the groups from one another was important as it

acknowledged differences in the timing of diary use throughout the critical illness journey. This was reflected further in the timing of interviews, with family members and nurses being interviewed around the time the patient was in ICU and patients being interviewed between three and six months after ICU discharge.

Rubin and Rubin (2012) note that qualitative interviewing

*“...requires intense listening, a respect for and curiosity about people’s experiences and perspectives, and the ability to ask about what is not yet understood.” (p. 6)*

Therefore, gaining trust and establishing rapport are essential to this process (Fontana & Frey, 1998). There is a need then to develop a ‘trusting personal relationship’ to encourage open, honest and detailed accounts (Rubin & Rubin, 2012, p. 6), especially when exploring peoples’ personal experiences, which might be of a sensitive nature.

With a traditional ethnographic approach, it is possible to build up relationships over time. However, focused ethnography is characterised by spending less time in the field with visits taking place in intervals rather than being continual (Knoblauch, 2005). The researcher got to know the nurses working in the unit from repeated visits, however patients and family members were frequently changing which meant that there was less time to build up a relationship prior to the interview taking place. Different ways in which the researcher can facilitate an effective relationship during the interview include: expressing an interest in what is being said; informing the participant that there are no right or wrong answers; observing body language and listening for clues in tone of voice; giving the participant time to reply; pacing the interview and trying to approach the subject fresh with each participant, which may help in unlocking a detailed account (Legard, et al., 2003). The researcher drew upon her experience as a nurse to facilitate relationships with participants as well as most of the techniques listed above, which appeared to work well.

Furthermore, the environment where an interview takes place is another important consideration for any researcher. It has been suggested that maintaining an environment appropriate for interview, may necessitate a compromise between



accessibility, comfort and level of distraction (Todd, 2010). The researcher was given access to a room situated near the ICU which was used as an additional consultation room for family members and for overnight stays, although it was often free as there were other designated areas in the department. The room was suitable for interviewing as there was comfortable seating, natural light and it was close to the ICU which made it accessible for visiting family members and nurses on duty. While being close to the ICU made it possible for nurses to be interviewed during their working hours, patient care took priority, which increased the risk of distraction and interruptions. Two out of the six nurse interviews were interrupted, yet both nurses returned to complete their interview during the same shift. There was minimal disruption to the flow of these interviews as the researcher had anticipated this may be an issue and made notes about the discussion at the time of the interruption thus allowing conversation to continue when the nurses returned.

The location of the room near the ICU appeared to be convenient for family members as well, who mostly wanted to be interviewed either before or after visiting in the ICU or hospital. Patients and family members were also given the option of a home visit for interview or a location of their choosing to increase accessibility. This was especially important for patients who were recovering from the physical, psychological and emotional impact of critical illness, often resulting in a prolonged recovery time and inability or unwillingness to return to the hospital. Three out of the four patients interviewed were interviewed at home and one, who had returned to work, decided to come back into the hospital for interview. Whereas, only one family member was interviewed at home, resulting from her husband being discharged from the hospital quicker than expected. While a home visit was more appropriate for patients there were different challenges with distractions in this environment, such as the phone ringing, dogs barking and other family members being present in the house, for example, young children. However, the researcher found that adult family members present in the house, who had already been interviewed for the study, were respectful of giving their loved one privacy and time to discuss their experiences.

Each interview was opened with an explanation of the purpose of the interview and how it would be conducted. To put participants at ease, the interview was described as a ‘discussion’ or ‘conversation’ where the researcher would ask some questions. Additionally, it was emphasised that the purpose of the research was to find out about the participant and their experiences with critical care diaries. Following on from this short introduction the researcher began by asking participants some background information to get them talking and start the flow of the conversation.

The researcher was fully aware from her own experience as a nurse working in an ICU environment that the experience of critical illness, including spending time in an ICU and recovering, can be highly emotive and effect everyday life. Therefore, it was anticipated that some participants might become distressed as they were being asked to discuss their experiences with critical care diaries, linked closely to critical illness and spending time in an ICU. Keeping this in mind the researcher informed participants at the start that they did not have to answer every question if they did not want to and details were included in the study protocol on managing distress. As expected there were some interviews where a patient or family member became upset and the researcher managed this by giving them time and the option to discontinue the interview, nevertheless all participants who became upset wanted to keep going. The ethical issues associated with interviewing will be discussed further in section 3.6.2.

### **Focused observations**

*“Qualitative observation is fundamentally naturalistic in essence; it occurs in the natural context of occurrence, among the actors who would naturally be participating in the interaction, and follows the natural stream of everyday life.” (Adler & Adler, 1998, p. 81)*

With a focused ethnographic approach, it is not essential to undertake observation as a method of data collection (Higginbottom, 2011). However, in this study it was decided to observe nurses performing diary related activities as the researcher had no previous experience with the use of critical care diaries in practice. Furthermore, there had been no published accounts of diary use in NHS Scotland where the research was situated. Therefore, it was anticipated that focused observations would allow the researcher to gain an insight into how this unit worked and the practical

aspects of how critical care diaries were used, thus providing background information and context to inform the interviews.

The observer role taken on by the researcher has similarities with the *observer-as-participant* role described by Morse and Field (1996) and the *peripheral-member-researcher* role described by Adler and Adler (1998). As an *observer-as-participant*, researchers have minimal participation in the work role and spend most of their time observing or interviewing, thus allowing them to carry out their research with less conflict, and establish their credibility as a researcher (Morse & Field, 1996). However, one of the key disadvantages of the *observer-as-participant* role is the researcher being viewed as an outsider by staff (Morse & Field, 1996). Furthermore, Roper and Shapira (2000) suggest that using only this role in ethnography is problematic as there is little opportunity for the researcher to confirm with participants what has been observed, which may lead to unfair interpretations of the event, action or behavior being studied. Whereas in the role of *peripheral-member-researcher*, researchers

*“...feel that an insider’s perspective is vital to forming an accurate appraisal of human group life, so they observe and interact closely enough with members to establish an insider’s identity without participating in those activities constituting the core of group membership.” (Adler & Adler, 1998, p. 85)*

The researcher spent on average two afternoons, approximately 8 hours, each week at the site screening for potential participants and for opportunities to observe diary related activities. During this time, the researcher joined staff in the break room and on the unit to speak to them about the study. For example, informing them of her intention to observe some of the activities they performed with diaries and to interview patients, nurses and family members. This helped to build up trust and develop a rapport with nursing staff as well as set clear boundaries on the researcher’s role.

The researcher was accepted as a nurse researcher and visiting member of staff but was never called upon as part of the work force. However, as noted by Holloway and Wheeler (2010) it can be difficult not to get involved when staff are visibly busy

and the researcher found herself assisting with small tasks such as answering the phone or the entry system, passing on messages and helping to put away disposable stock in the storage room. These small voluntary actions were not intentionally planned and were not expected of the researcher, yet felt normal to the researcher who was in a familiar environment. Furthermore, assisting with these tasks helped to pass the time when waiting to speak to members of the nursing or medical team about potential participants or on family members coming in.

When it came to observing a planned activity or interaction, the researcher did not participate in any way, other than through being present and observing the nurse.

*“Simple observers follow the flow of events. Behaviour and interaction occur as they would without the presence of the researcher.” (Adler & Adler, 1998, p. 81)*

Nurses were encouraged to inform the researcher if they believed the presence of the researcher was affecting the care they were delivering to patients and their family members. Likewise, it was made clear to patients and family members present that the researcher would discontinue her observation and leave if they wished to change their mind about the researcher being present and observing the nurse.

Observations were planned to take place in the clinical practice settings of the ICU, hospital ward and at the follow up clinic. These areas were identified from the diary literature as areas where diary related activities with patients and family members are undertaken by nurses. The length of the observation was dependent on the activity. For example, observing nurses handing over the diary to the patient was often shorter than observing nurses during a follow up appointment with a patient and their family member present. Therefore, observations ranged from around 15 to 45 minutes in length.

Observation schedules were developed by the researcher to provide structure and consistency to the information recorded, including details about the activity, environment, who was involved and the actions of the nurse (see Appendix 6). Preliminary notes were made by the researcher prior to, during and after each observation. The notes did not include any identifiable information or information

relating to patients and family members. After each observation event there was often an opportunity to discuss with the nurse what had been observed and the researcher's understanding of the activity, in keeping with the role of *peripheral-member-researcher*. This added to the credibility and therefore trustworthiness of the observational data collected, as outlined in section 3.7.1. Furthermore, notes were completed fully after the event and data generated from the observations was managed in a similar way to the interview data as outlined in section 3.5.6 as well as being used to inform ongoing data collection and the analysis, see section 3.5.7.

Observing as a method of data collection in the social sciences has been described as the 'least obtrusive' method by Adler and Adler (1998, p. 101) who recognise that this may lead to ethical concerns around invasion of privacy. Ethical considerations of the study are discussed later in section 3.6 however it is important to mention that this aspect of the study provided challenges in gaining ethical approval. The researcher proposed that observations would focus only on nurses with the main purpose of the observations being to gain an insight into the nursing practice of diaries, as experiences including thoughts and feelings cannot be observed (Roper & Shapira, 2000). However, due to the setting and nature of these activities family members and patients would be present. It was therefore requested by the ethics committee that family members and patients, in addition to nurses carrying out the activity, provided a face-to-face written informed consent prior to any observation taking place. Observations of nurses performing diary related activities were therefore limited, especially in the ICU where patients did not have capacity to provide written informed consent.

A total of 9 observations took place, with only two of these in the ICU, whereas the researcher had estimated and gained ethical approval for 15 to 20 observations. Furthermore, the natural flow of events was interrupted with the researcher having to explain to patients and family members that the nurse was about to introduce them to a diary, which they potentially knew nothing about. Generic information leaflets were available in the visitor's room and on the unit while the research was going on and, where possible, one of the nurses from the ICU introduced the researcher to the

patient in the ward, however often this was not possible and a member of ward staff who knew little about diaries was asked to do this.

Focused observations and semi-structured interviews occurred during the first few months at the site as separate data collection activities. Once several key diary related events had been sampled for the focused observations the observations became less important and eventually stopped, however recruitment to the semi-structured interviews continued.

### **Photographs of diary entries**

At the time of designing the study diaries were not widely used in Scottish ICUs, which was confirmed when selecting a setting for the study to take place. Only a small number of units had used or were using diaries in Scotland and the practice was relatively new. Therefore, it was believed that having some example diary excerpts would be useful as a visual aid to help people who were unfamiliar with this nursing intervention understand what it was. There was no intention to analyse this data formally as it was gathered merely to supplement and illustrate findings from the semi-structured interviews.

As diaries are written to and for the patient it was necessary to obtain permission from the patient to access their diary. The researcher asked participants if it was possible to look at their diary during the study. Consent was sought from related family members and patients selected for interview and access to the diary took place once a consensus had been gained from both parties. It was anticipated that there may be situations where the patient was no longer able to give permission and the ethics committee agreed the researcher could access the diary in these circumstances with only the family member's consent. However, when a potential patient participant died several weeks after being discharged home the researcher did not feel it was appropriate to ask to see the diary, which by that time was in the possession of the bereaved family. Furthermore, it was requested by the ethics committee that access to the diary was clearly documented in the participant information sheets and consent forms as an optional aspect of the study.

Photographs of the example diary entries were taken during the same visit as the patient interview, once the interview had finished. The researcher wanted to gather a range of different examples of diary entries and when certain diary entries were referred to in an interview an effort was made to find these. The researcher was guided by the patients, who sometimes pointed out an entry they thought might be a good example to have. Each entry photographed was checked with the patient, to confirm they were happy that this could be used as an example diary excerpt.

### 3.5.6 Data management

The following sections on data management give a detailed account of how data was generated and organised in preparation for data analysis.

#### Recording interviews

Interviews were recorded using a digital voice recorder, on loan from the university for the period of data collection. The main rationale for recording interviews was to avoid important information being forgotten and to facilitate the selection of direct quotes from participants, which would later help to illustrate the findings. By using a digital recorder, the researcher only had to make occasional notes as reminders to discuss certain topics further, thus allowing her to maintain eye contact with participants and concentrate on what they were saying. Holloway and Wheeler (2010) recognise the benefits of recording interviews stating that

*Before analysing the data, researchers must preserve the participants' words as accurately as possible. The best form of recording interview data is tape-recording. (p. 95)*

In recent years, there has been a move towards audio-recording interviews digitally as the quality of the recording is said to be 'far superior' and it is possible to filter out background noise, therefore making it easier to transcribe the interview (Bryman, 2008). Furthermore, it is easier to back-up the recordings and replay small sections again and again to assist with transcription. However, despite the advancements in technology and whether a tape recorder or digital recorder is used, it is possible that some participants may not want to be recorded and researchers must respect this in keeping with the ethical principle of respect for autonomy (Holloway & Wheeler, 2010). Participants have a right to refuse participation and this right can be exercised

at any point in the research process (Holloway & Wheeler, 2010). In this study, participants were informed that the interview would be recorded and this was detailed clearly in the participant information sheets and consent forms.

Additionally, the researcher confirmed before starting each interview that the participant was still in agreement for the interview to be recorded, with the understanding that the interview and recording could be stopped at their request without giving a reason, to which all participants agreed.

Prior to attending an interview, the researcher performed various actions to ensure the quality of the recording. These included checking the battery life, testing the record and playback function on the digital voice recorder and checking the volume was set at an adequate level to record the interview. Additionally, during each interview the researcher checked the recorder a few minutes in, to ensure the red recording light was on. As a back-up measure, spare batteries and a second digital recorder were available, fortunately, these were never required. This level of checking before and during the interview process originated from discussions with more experienced researchers in the critical care team and recommendations from a qualitative interviewing course the researcher attended at the University of Oxford.

With regards to recording interviews Rubin and Rubin (2012) state that

*“Recording should be as smooth and unobtrusive as possible so that it does not distract either you or your interviewee.” (p. 100)*

To achieve this, the researcher placed the recorder outside the participant’s direct line of site, so as not to act as a distraction. This technique worked well, with both the researcher and the participant taking little note of the recorder during the interview, apart from a quick check at the beginning of the interview as already mentioned. When the interview was complete the digital file was saved with the participant ID and date of interview. This was later backed up on a computer by uploading the recording as an MP3 audio file to a secure password protected folder, which only the researcher had access to.



## Preparing interviews for analysis

The process of preparing interviews for analysis involved transcribing the audio-recordings of interviews into Microsoft word with a separate word file for each interview. The transcripts were then imported into NVivo version 9 (NVivo) which is a Qualitative Data Analysis Software (QDAS) programme, later upgraded to NVivo version 10. This section will discuss the process of transcription and highlight decisions made by the researcher around this process, followed by a brief overview on the use of QDAS which is used to store and manage different forms of qualitative data.

The process of transcribing qualitative data from interviews is recognised as

*“...one of the initial steps in preparing the data for analysis.”*  
(Holloway & Wheeler, 2010, p. 282)

Transcription is a common practice in qualitative healthcare research yet, Wellard and McKenna (2001) note that there is little discussion in the nursing and allied health professional literature on transcription and the techniques used during this process. A later article published in the *International Journal of Qualitative Methods* by Davidson (2009), reviewing three decades of transcription literature, noted that this process is often ‘overlooked’ in qualitative research, therefore this appears to be an ongoing issue which is not just relevant to qualitative healthcare research.

Transcription is one of the methods used in this research study and the process of transcription will therefore be made clear, as recommended by Wellard and McKenna (2001).

There are various decisions to be made around the process of transcribing interviews, starting with who should transcribe, what to transcribe from the interviews and how this should be represented in text (Lapadat & Lindsay, 1999). In this study, the researcher was responsible for transcribing all the interview data which proved to be beneficial as it helped in getting to know the data. Through transcription the researcher can begin to immerse themselves in the data, developing an intimate knowledge of the data and becoming sensitive to important issues arising (Holloway & Wheeler, 2010; Bazeley, 2013). Transcribing took a significant amount of the

researcher's time, which in this study was further affected by deciding to transcribe the interviews verbatim. On average, the interviews in this study lasted between 40 to 60 minutes taking the researcher around eight to ten hours per interview to transcribe. With practice this became quicker and the researcher could transcribe around ten minutes of interview per hour, although this was still a considerable amount of time spent on transcribing. Lathlean (2010) note that even with the assistance of a transcription service, an hour of interview can still take several hours to transcribe. Furthermore, once the transcript is returned to the researcher it is recommended that they check this against the audio recording of the interview so that missing or incorrect words and punctuation potentially affecting the meaning of a sentence can be corrected (Bazeley, 2013).

A draft of the audio recording was created as soon as possible after the interview by listening to the recording at a slower speed. The draft transcript was then rechecked for accuracy against the full audio recording. The researcher developed this process after transcribing the very first interview and found it to be more time efficient to firstly create a draft knowing that incorrect or missing words and phrases could be picked up later and the transcript amended as necessary. Rubin and Rubin (2012) advise that transcribing should take place as soon as possible after the interview. Benefits of doing this include being able to remember what was said, which can help if parts of the recording are unclear, as well as identifying important issues to be addressed in future interviews (Rubin & Rubin, 2012).

Transcribing verbatim has been recommended to gain the 'fullest and richest' data (Holloway & Wheeler, 2010). However, McLellan et al (2003) note that the decision around what to include in a transcript should be informed by the research question or questions the analysis aims to answer. The research aim and questions in this study relate mainly to people's experiences, therefore the decision was made to include all content from the interviews in the transcript to be able to explore in detail those experiences. As a novice researcher with little experience of the transcription process, it did not become apparent until attempting to transcribe the first interview that other decisions around what to include in the transcript were required. Oliver et

al (2005) provide useful discussion in this area noting that transcription practices can be viewed on a continuum between two main methods. These are:

*“...naturalism, in which every utterance is transcribed in as much detail as possible, and denaturalism, in which idiosyncratic elements of speech (e.g. stutters, pauses, nonverbal, involuntary vocalisations) are removed.” (pp. 1273 - 1274)*

It is possible for the researcher to draw upon aspects of each method however Oliver et al (2005) recommend that researchers reflect on their transcription choices in relation to how these may affect participants and the overall aims of their research. Furthermore, a consistent approach should be taken (Wellard & McKenna, 2001). With regard to participants, one of the main concerns was around maintaining confidentiality and anonymity. Therefore, all participants, people and places mentioned in the interview were given pseudonyms, detailed further later in this section. Additionally, when transcribing the researcher found the use of the Scots dialect and the participant's accent challenging, despite being native to Scotland. This issue was unexpected and did not present as an issue until transcribing the first interview.

Initially the researcher found herself translating what the participant was saying into Standard English which made the researcher feel uncomfortable. The participant's voice appeared to have been lost when reviewing the first few minutes of the transcribed interview and an unfamiliar account appeared on the page, raising concern that the meaning of what had been said could potentially be lost through translation and this way of transcribing. For example, a quote taken from the first interview demonstrates how the participant's words were changed, when translated into Standard English. The original quote is in green and the translation into Standard English follows in black

*“...aye it's good to write the funny things that happened at home wi oor wee grandson.” (Angela FM1)*

*“...yes it is good to write the funny things that happened at home with our little grandson.”*

This highlighted to the researcher the importance of preserving the natural language used by each participant. The researcher therefore, to begin with, took more of a naturalised approach to transcribing. However, this was challenging as some participants had quite a strong accent, specific to the region in Scotland where the research was conducted and adding further to the overall time it took the researcher to transcribe.

Once completed, each interview transcript was imported into NVivo. The researcher attended several training events provided through the university to learn how to use NVivo and the decision to eventually use this was based on being able to store and access multiple sources of data in one place as well as learning a new research skill that could be used with future projects. Bazeley and Jackson (2013), who have written a book specifically on qualitative data analysis with NVivo, suggest that this can help with managing data, ideas, querying and visualising data and reporting from the data. Further detail on how this software was used to assist in the early stages of analysis will be provided in the data analysis section 3.5.7.

### **Observations, field notes and diary entries**

In addition to the interviews and as outlined in the section on data collection techniques, other sources of data were generated in this study. While the interviews provided the main source of data, it is important to outline how these additional sources were managed and prepared to assist with the data analysis process. Firstly, it should be mentioned that all sources of data from this study were imported into NVivo and stored as 'Internals'. Internals are the primary source materials (Bazeley & Jackson, 2013) which, for this study, were organised into the subfolders of interviews, observations, field notes and photographs of diary entries.

Observations and field notes were transcribed directly from the original written source documents into word files and then imported to NVivo. As with the interview audio recordings these documents were transcribed as soon as possible after the event. However, they contained no identifiable data which was filtered out by the researcher at the time of creating the original source document. Separate logs were created to keep track of the observations and interviews (see Appendix 7). Whereas the field notes, recorded in a note book, were transcribed directly into a single word

document organised in chronological order, thus mirroring the original content of the researcher's field diary.

Examples of diary entries were obtained during the patient interviews with a digital camera. The photographs were uploaded to the computer as a JPG file. This file was labelled with the patient ID from the interview and a description of what the diary entry was. For example, one of the example diary entries obtained from the second patient participant was labelled P2 Nurse 'first' diary entry (see findings chapter section 4.3.1 this diary excerpt). Once uploaded and saved to a secure password protected file on the computer, the digital images on the camera were deleted.

In summary, a detailed overview has been given to ensure transparency of the data management process undertaken in this study. Various measures were taken to manage and prepare the data for analysis, reflecting the multiple sources of data collected for this study. However, the way in which the interviews were managed received the most attention as they were the most time consuming and challenging aspect of the qualitative data to organise. All data were; anonymised, uploaded into an electronic format on the computer in the form of a word document or in the case of photographs a JPG file, labelled appropriately and then imported into NVivo 9 in preparation for the process of data analysis.

### **Maintaining confidentiality and anonymity**

Ethical considerations of the study will be discussed later in section 3.6 however several measures were taken in managing the data to protect and maintain confidentiality and anonymity of research participants. All interview participants were allocated a pseudonym and a code made up from a letter(s) indicating what group they belonged to. FM for family member, N for nurse or P for patient and a number indicating their triad. Numbers were allocated sequentially starting with the number 1. The original interview audio recordings were only ever accessed by the researcher and all interview recordings were uploaded to a secure password protected file and deleted from the digital recorder. As each interview was transcribed, identifiable information such as names and places were changed and replaced with pseudonyms to maintain confidentiality and anonymity.

Observations were labelled sequentially using the letter O followed by a number. For example, the first observation was O-01, the second O-02 and so on. The researcher's written notes from the observations did not contain any identifiable information which was the same for the researcher's field diary. Handwritten diary excerpts were anonymised using small rectangles of black card to cover names and other identifiable information prior to taking a photograph of the entry. This had been suggested and agreed with the local R&D department. However, there was a limited amount of time available for the researcher to select and check diary entries before capturing an image with the camera, as this activity occurred at the end of the patient interviews. Therefore, the JPG files were closely inspected once uploaded to the computer and where necessary edited. This included removing dates of diary entries as suggested by the researcher's supervisors on the basis that this information was not essential and would help to anonymise the diary entries further by not knowing when they had been written, although it was agreed to keep the time if this had been documented.

### **3.5.7 Data analysis**

A thematic approach to analysis was selected to analyse the data in this study. The approach used was based on the six phases of thematic analysis outlined by Braun and Clarke (2006, p. 87) in Table 5.

Table 5: Six phases of Thematic Analysis

Phase	Description of the process
<b>1. Familiarising yourself with your data</b>	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas
<b>2. Generating initial codes</b>	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code
<b>3. Searching for themes</b>	Collating codes into potential themes, gathering all data relevant to each potential theme
<b>4. Reviewing themes</b>	Checking if the themes work in relation to the coded extracts and the entire data set, generating a thematic 'map' of the analysis
<b>5. Defining and naming themes</b>	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme
<b>6. Producing the report</b>	The final opportunity for analysis, selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research questions and literature, producing a scholarly report of the analysis.

Braun and Clarke (2006) take the view that thematic analysis is an analytic method and is therefore not attached to any specific theoretical or epistemological position.

They state that

*“...thematic analysis provides a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex, account of data.” (Braun & Clarke, 2006, p. 78)*

Flexibility in this method means that it can be applied to a range of different research interests and theoretical perspectives to identify, analyse and report on patterns or

themes within the data (Braun & Clarke, 2006; Clarke & Braun, 2013). Furthermore, thematic analysis is regarded as a foundational method for qualitative analysis, providing the researcher with key skills that are applicable to other types of qualitative analysis (Braun & Clarke, 2006). This method can be applied to a variety of research questions, types of data, large or small data-sets and used for data-driven or theory-driven analysis (Clarke & Braun, 2013). A thematic approach to analysis also allows for the comparison of groups defined in the research question and acknowledges that in different groups different views may be found (Flick, 2009), therefore making it appropriate for use in this study.

Holloway and Todres (2010) note that in ethnography, analysis is an iterative process rather than linear. Thus, researchers move between collecting, reading and thinking about data to the analysis which continues until the data collection and analysis are complete (Holloway & Todres, 2010). Braun and Clarke (2006) recommend that their six phases of thematic analysis are to be taken as a guideline, therefore recognising the need for qualitative researchers to be able to move back and forth as described by Holloway and Todres (2010). As with other stages in the research process and the methods used, there are various decisions to be made around the thematic analysis approach, which should be considered before analysing the data (Braun & Clarke, 2006). The following discussion around how the researcher analysed the data will highlight and address issues relevant to this research.

Bazeley (2013) recommends taking time to become familiar with each source of data through reading and reflecting on it as it becomes available. This, along with the process of transcribing, outlined in the previous section 3.5.6 on data management, is the first phase in conducting a thematic analysis. Richards and Morse (2007) refer to this early phase of data analysis as ‘getting inside’ the data which they note is easier for researchers who have been involved in collecting the data, writing field notes and transcribing. The researcher listened to the audio-recordings of the interviews on the same day that they were created. The interview transcripts, observation transcripts and field notes were read through as soon as they had been completed after each event. This helped the researcher become familiar with the data as suggested by



Bazeley (2013), and provided an opportunity for the researcher to identify further areas needing follow up during the recruitment and data collection phase.

In this study, interviews provided the main source of data and were treated as a separate data-set from the observation transcripts and field notes, as these provided background and context to inform and situate the study. The three sources of data, separated into two datasets for the analysis, were merged in the final stages of analysis when reviewing, naming and defining the themes and writing up the final report, as seen in the findings chapter. Excerpts of observation transcripts and fieldnotes detailing personal reflections were incorporated to supplement the main findings from the interviews. As mentioned already, the photographs of diary entries were not analysed and therefore used only for illustrative purposes to provide the reader with diary entry examples.

The researcher started with paper copies of the data from each data-set and began to write down her initial ideas. However, as noted by Richards (2009), working with paper requires several copies to be made so that data about a topic or concept can be accessed, meaning that the same segment of data is often stored in several different files, a process criticised for being time consuming, boring to organise and lacking rigour. Furthermore, as the volume of data began to increase and the researcher moved towards the second phase of analysis, involving the generation of codes, working with paper copies became messy and unmanageable. At this point the researcher moved onto using NVivo, where all the data was already being stored electronically, as detailed in section 3.5.6.

An early criticism of using software for qualitative data analysis is that researchers can feel distant from their data (Gibbs, et al., 2002). However, from the researcher's experience it was possible to remain close to the data by having a system that allowed the researcher to manage the data more easily. Furthermore, significant time had already been spent familiarising with the data as it was collected and prepared for analysis. Benefits of using QDAS include: a faster and more efficient way of coding data; the ability to store more information; categories or codes are linked to coded segments; it is easy to move from coded segments to the original context; and there is the possibility of being able to ask questions about patterns of coding

(Richards & Morse, 2007). The researcher experienced most of these benefits however did not go as far with the software to ask questions about patterns of coding. Although training had been undertaken with NVivo, it was not until using this for her own research that the researcher began to learn and feel comfortable with this software, which was used initially for coding.

The researcher originally planned to start by analysing each triad, believing that experiences discussed by nurses, family members and patients would cross over within that triad. However, through interviewing nurse participants and spending time familiarising with this data it became apparent that nurses very rarely referred directly to the family member or patient in the same triad, even when prompted in the interview by the researcher. Nurse participants' experiences and perceptions were drawn from a wider range of experiences with diaries in the ICU, involving different situations with different patients and family members during the time they had worked in the unit. Whereas patients' and family members' experiences and perceptions were mostly related to one critical illness experience or event, apart from one family member and patient who had dual experiences from both the family member and patient perspective in the same ICU. Therefore, the decision was made to start by coding all interviews in the same group before moving onto the next group. The patient group was the first group to be coded as there were only four participants, this was followed by family members and then nurses.

Coding involves the researcher labelling sections of text based on their understanding of what that section of text is about (Bazeley, 2013). Richards and Morse (2007) however emphasise that coding is not just about labelling it is also about linking. They state that coding

*“...leads you from the data to the idea, and from the idea to all the data pertaining to that idea.” (Richards & Morse, 2007, p. 137)*

Different types of codes can be used to help focus and develop ideas (Bazeley, 2013). Richards and Morse (2007) identify three types of coding used in qualitative research. These are descriptive coding, topic coding and analytic coding. A

combination of these types of coding were used in this study and will now be outlined.

Descriptive coding allows the researcher to store ‘known’ or ‘factual’ information, for example, information about participants such as age and gender. This information can be built into how the data is managed, with the relevant characteristics included in each data document or as a table that can be imported. In this study, descriptive coding was applied to the interviews, observations and diary entries. This information related to the participants involved, the event and the context in which this took place. Keeping track of the data in this way, as it was collected, helped to guide purposive sampling of participants and diary related events thus informing the ongoing data collection.

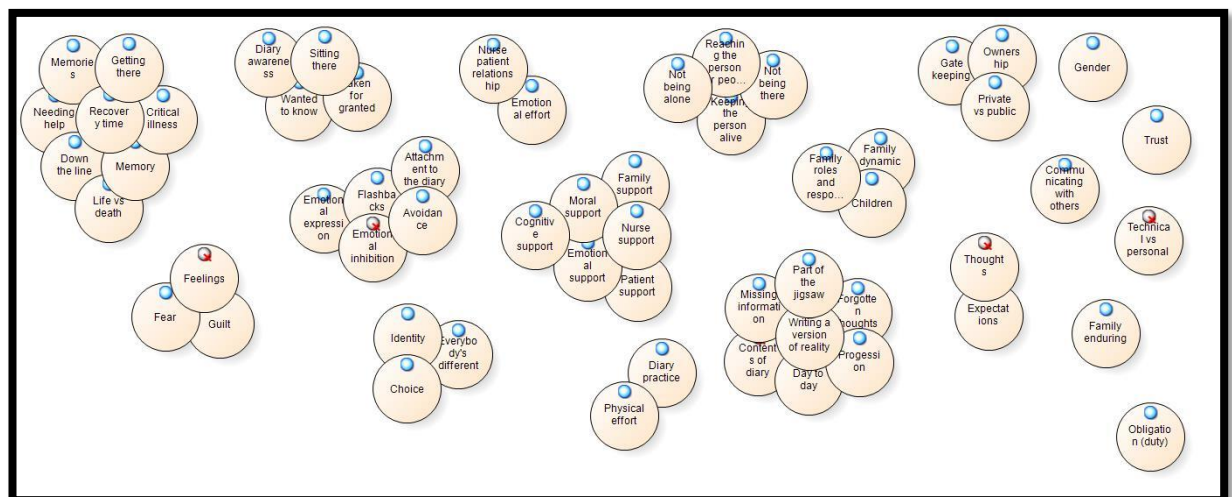
Topic coding involves creating categories and is useful in the early stages of analysis for the researcher to explore what is in the data (Richards & Morse, 2007). Topic codes can be descriptive or interpretative, in this study both were used however as the process of analysis progressed, codes became more interpretative. Occasionally participants’ own words were used to create codes. Each code created in NVivo version 9 was given a description which made it possible for the researcher to review existing codes as new ones were created, some codes were combined or became sub codes of others. Throughout the process of coding, sections of data and codes were reviewed with the researcher’s supervisors. This activity has been referred to as ‘peer debriefing’ (Lincoln & Guba, 1985) or ‘peer review’ (Holloway & Wheeler, 2010) and was adopted to support the trustworthiness of the research process and findings, discussed further in section 3.7.4.

As with the overall process of analysis in qualitative research, the researcher found herself moving back and forth through the data, coding and re-coding as new categories or codes were created. Richards and Morse (2007) note that as coding continues and more categories are created the process of coding becomes more analytic. They state that

*“...in creating categories you go on, not just linking them to the data but also questioning the data about the new ideas developing in the new codes.” (Richards & Morse, 2007, p. 141)*

Analytic coding can help the researcher identify new meanings or themes in the data, enable the exploration and development of new ideas and seek comparisons (Richards & Morse, 2007). This level of coding was performed only with the interview data-set. The observation transcripts and field notes containing reflections from the interviews, focused observations and informal discussions at the site provided context and therefore assisted with understanding. Furthermore, the researcher created memos on NVivo while coding to record her thoughts as the analysis progressed. These notes were separate from those documented in the reflexive journal as NVivo made it possible to link comments directly to the codes or the source, for example, sections of an interview (Bazeley & Jackson, 2013).

As coding continued the researcher began to use the model function in NVivo to sort through and visualise the code structure, as demonstrated in Figure 6.



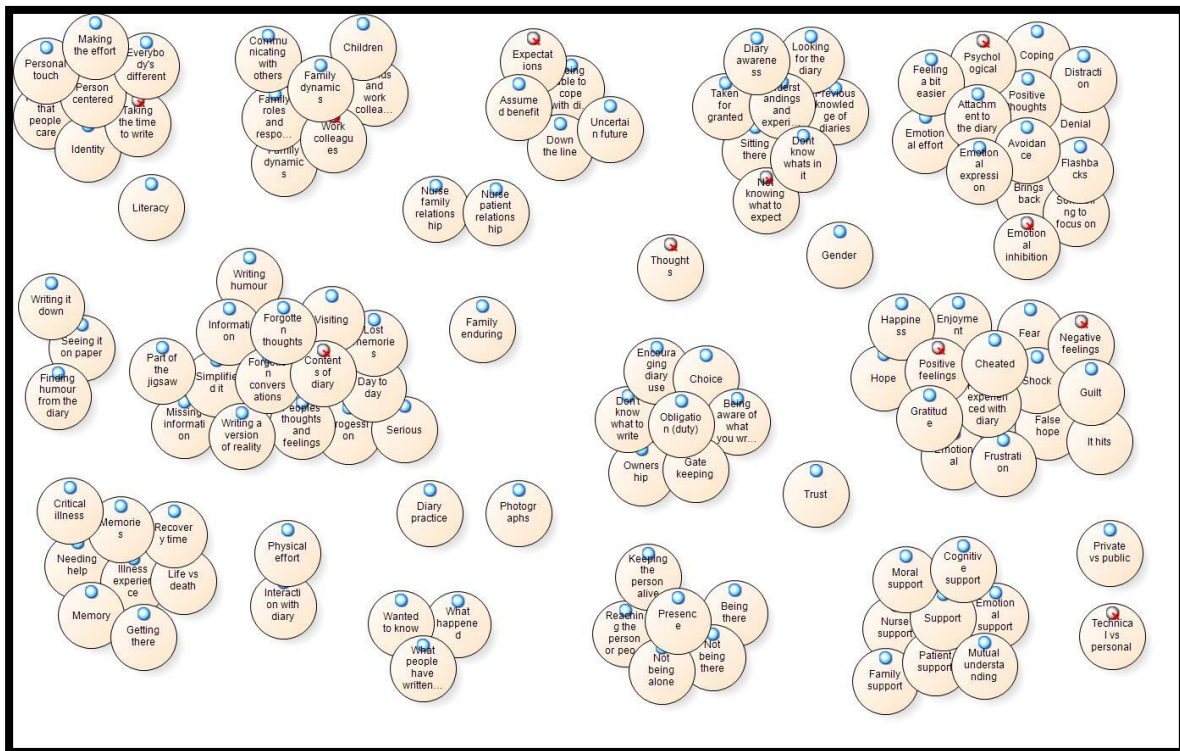
*Figure 6: Early conceptual model of code structure with NVivo version 9*

Visualisation of data in this way can help early in the process of working with data as it allows the researcher to see large amounts of data on one page which may help in identifying relationships and patterns in the data (Bazeley & Jackson, 2013).

Furthermore, the process of grouping codes together provides the researcher with a way into the data to search for themes. However, as the number of codes increased it became more difficult to do this with eventually over 300 different codes created

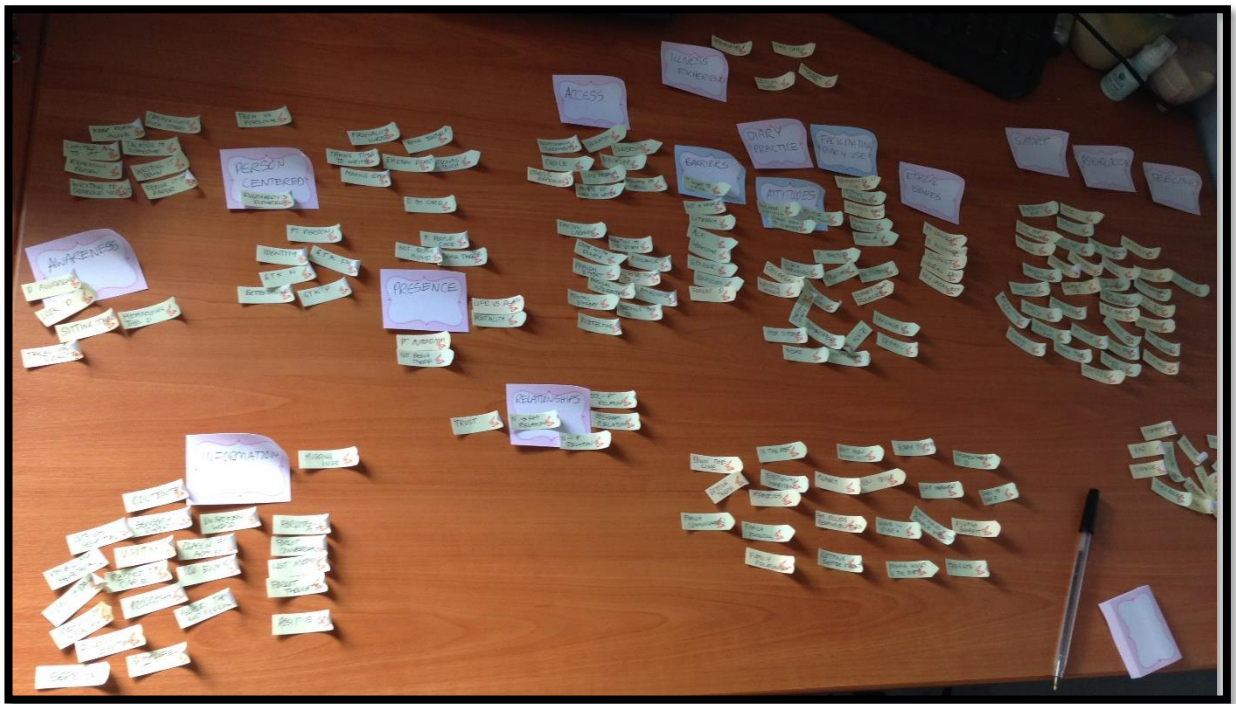
from coding all the interviews in each group of patients, family members and nurses.

Figure 7 provides an example of a model the researcher created with more than 120 codes.



**Figure 7: Later conceptual model of code structure with NVivo version 9**

The researcher manually recreated the modelling function from NVivo by writing out every code on a separate post-it note and sticking it to her desk. Photographs were taken by the researcher to document the development of themes, which were represented with larger post it notes as seen in Figure 8.



**Figure 8: Conceptual model of code structure created manually**

This activity helped with the process of searching for and reviewing themes. In searching for themes the analysis is focused at the broader level of themes, involving the sorting of codes into potential themes, which consist of main themes and sub themes (Braun & Clarke, 2006). Whereas reviewing the themes occurs on two levels with level one checking the themes against the coded extracts and level two examining the themes in the context of the complete data-set (Braun & Clarke, 2006), which in this study was the interview data-set.

Braun and Clark (2006) note that

*“A theme captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set.” (p. 82)*

It was therefore important for the researcher to consider the meaning of the emerging themes in each group, across groups and within the triads to answer the research questions and overall aim. Figure 9 shows the early development of the theme ‘information’ which was created from an initial code and later became one of the



main themes in the findings, which will be presented later in the findings chapter, section 4.3.



Figure 9: Early development of the theme 'Information'

The final phase relating to themes, involves defining and naming the themes where themes presented for the analysis are refined further. Braun and Clark (2006) explain that this is about

*“...identifying the ‘essence’ of what each theme is about (as well as the themes overall), and determining what aspect of the data each theme captures.” (p. 92)*

Furthermore, the researcher creates definitions and final names for each theme to be given in the final analysis so that the reader has a clear idea as to what each theme is about (Braun & Clarke, 2006). Producing the report (findings) was the final activity undertaken in the thematic analysis which is presented fully in the following chapter. Exploring themes within the triads and drawing on the data-set of observation

transcripts, field notes and diary entry examples enabled the researcher to illustrate and explain the themes, as well as selecting quotes from the interviews.

Once quotes had been selected they were prepared for use in the thesis. As discussed earlier on in the chapter, the researcher decided to preserve the natural language used by each participant, see section 3.5.6. However, some quotes were difficult to read and understand which was confusing and distracting when trying to read and understand the quote. Thus, the original intention to keep participant's voices by transcribing their natural way of speaking had to be adapted further to ensure that the meaning of what was being said was not lost and their voices could be understood. The researcher created a document to clearly outline how the quotes were prepared for use in the thesis (see Appendix 8) and a glossary of the Scots words kept in the quotes which are presented in the findings chapter, section 4.2. As each quote was selected and reviewed, certain words were replaced. The main reasons for replacing words were that some words were not used very often or were specific to an individual participant's accent rather than the common dialect or Scots language, some words had more than one meaning, or there was more than one word or way of saying the word. For example, the word 'myself' appeared in transcripts as 'myself', 'maself', 'masell' so for consistency all versions became 'myself'. Therefore, the final quotes selected and presented in the findings chapter of the thesis went through a further process which had not been anticipated at the time of transcribing.

### 3.6 Ethical considerations

Ethnography in a healthcare setting presents the researcher with certain ethical challenges, arising mostly from the close relationships developed with participants which are

*"...unlike that found in other research designs." (Roper & Shapira, 2000, p. 113)*

Consequently, the researcher is required to adopt specific strategies throughout the research process to maintain ethical relationships with group members, including the provision of 'truthful' and 'specific' information to allow participants to make an informed decision about their participation in the study (Roper & Shapira, 2000).



The moral principles of respect for autonomy, non-maleficence, beneficence and justice, outlined by Beauchamp and Childress (2013) in the 7<sup>th</sup> edition of their book *Principles of Biomedical Ethics* are used as a framework to discuss the ethical considerations for this study. Each principle is introduced, followed by discussion around how they apply to this research and what measures were taken to uphold those principles.

### 3.6.1 Respect for autonomy

The principle of respect for autonomy acknowledges a person's

*“...right to hold views, to make choices, and to take actions based on their values and beliefs.” (Beauchamp & Childress, 2013, p. 106)*

With regards to participation in healthcare research, it is therefore important that the researcher respects the autonomy of potential research participants on deciding if they wish to take part or not (Gelling, 1999). Beauchamp and Childress (2013) note that respect should involve, in addition to a respectful attitude, respectful action. Furthermore, in discussing respect for autonomy Beauchamp and Childress (2013) highlight that there are negative and positive obligations associated with autonomy. Autonomy as a negative obligation requires that autonomous actions are not controlled by others. For example, during the process of informed consent there should not be any controlling influences that may impact on the decision made. Whereas autonomy as a positive obligation requires consideration of how information is disclosed and the actions that help to promote ‘autonomous decision making’ (Beauchamp & Childress, 2013). These different aspects of autonomy are associated with various moral rules listed as; telling the truth; respecting the privacy of others; protecting confidential information; obtaining consent for interventions and when asked, helping others make important decisions (Beauchamp & Childress, 2013, p. 107), which are all relevant to the conduct of this study.

In this study, autonomy was respected through the process of informed consent with all participants. This involved explaining and providing information about the study to allow potential participants to make an informed choice. Separate consent forms and participant information sheets were created for each group and the research

activities they were invited to participate in. On approaching potential participants, the researcher made it clear that they had the right to refuse without any consequence from making this decision. For example, it was explained to family members in the ICU if they refused to participate this would not affect the care their relative received, which was detailed clearly in the consent and participant information sheet (PIS). Furthermore, it was clearly stated on all the consent forms that participation was voluntary and participants could withdraw from the study at any time.

Interviews with patients occurred after the time in ICU so it was unnecessary to recruit patients during the time in ICU when they were likely to be incapacitated. Therefore, the decision was made early on to only approach patients when they had regained capacity, as assessed by the clinical team. However, as the study was related to critical care and the researcher planned to observe diary related activities, performed by ICU nursing staff and potentially taking place in the ICU, ward or at follow up appointments it was advised to submit the study to Scotland A Research Ethics Committee, who deal specifically with research in adults with incapacity and are familiar with reviewing critical care research studies.

A letter was issued following the ethical review stating the committee were unable to give a favourable opinion. Further information was requested to be submitted for review by a sub-committee before confirming a decision. It was requested that written consent of patients and family members should be obtained prior to any observations of diary related activities performed by nurses. Endacott (2004) explains it is common to seek verbal assent from family members and patients for the researcher to be present, to observe and record nursing activities. However, in circumstances where an intervention is standard ICU practice or no intervention is undertaken, ethics committees may differ in their decision and as demonstrated from the conditions of the approval for this study it is not unheard of for a committee to request written consent from patients or their next of kin (Endacott, 2004).

Further minor issues including clarity in the study protocol on how diary data would be transferred to a hard drive and changes to the patient and family member PIS, making it clearer that it was optional for the researcher to have access to sections of the diary, were requested. These requests were in keeping with the moral rules of

respect for privacy and protecting confidential information. Additionally, the committee asked for a more systematic approach in the research design to the selection of patients, family members and nurses for interview. Following submission of the requested information, including changes to the study protocol and PIS for patients and family members, a favourable ethical opinion was granted pending local R&D management approval which was awarded shortly after, as detailed earlier on in section 3.5.2 on gaining access.

### 3.6.2 Non-maleficence

The principle of non-maleficence

*“...obligates us to abstain from causing harm to others.” (Beauchamp & Childress, 2013, p. 150)*

While there was no intention to cause harm to others through undertaking this research it was important for the researcher to consider any potential risks associated with this process. Hammersley and Atkinson (2007) note that while ethnography may not include the same risks as those associated with participants involved in medical experiments it can sometimes have consequences. These consequences can occur from participation in the research or from publishing findings. They note that participation may create or worsen anxiety and when conducting research in stressful situations careful consideration must be given to the effects this may have on those involved (Hammersley & Atkinson, 2007).

The main areas of concern identified in this research were related to the interviews with patients and family members. Rubin and Rubin (2012) note that part of the researcher’s ethical responsibility towards the interviewee is ensuring they come to no harm. They suggest that

*“Your interviewees should be no worse off, and ideally should be better off, for having taken the time to talk with you.” (Rubin & Rubin, 2012, p. 89)*

However, as discussed in the introductory chapter of the thesis, the experience of critical illness and recovering from a critical illness can lead to psychological and emotional problems for patients and their family members, therefore these groups are

potentially vulnerable, when entering the research process. Rubin and Rubin (2012) suggest avoiding interview questions that could cause harm. However, while the overall aim of this research was to gain an understanding of the different perspectives and experiences of critical care diaries, diaries are linked to the time in intensive care, the critical illness and patient and family member experiences of this. Therefore, it was possible that the interview might prompt distressing thoughts or memories through discussing experiences with the diary.

Rubin and Rubin (2012) in Chapter 6 note that some topics will potentially stir up emotions and advise researchers to give interviewees the option of answering a question or not, by explaining that the question might be too difficult or stressful to answer. This technique ensures that participants do not feel under pressure to answer, in the same way that they should not feel under pressure to participate in the research in the first place, relating to the principle of autonomy discussed in the previous section. The participant information sheets explained this potential risk and a section was included in the study protocol, outlining what the researcher would do if someone became distressed, as seen in Figure 10. However, although some participants did become upset during their interview, all wished to continue after pausing for a short time.

As detailed in the literature review chapter, there are thought to be potential risks associated with critical care diaries. For example, reading the diary is an emotional experience for patients (Engström, et al., 2008) and there is concern that diaries may potentially cause harm if given without the provision of appropriate psychological support (Phillips, 2011). Discussion in this area, focusing on the potential psychological impact of diaries, cautions against routine clinical use until further evidence is developed (Aitken, et al., 2013). The main concern associated with the safety and effectiveness of diaries relates particularly to the method in which diaries are provided (Ullman, et al., 2015). In the unit where the study was conducted diaries had been used as part of a follow up service for 3 years. Nursing staff were experienced in handing over diaries to patients and tailored this process to each individual patient. Additionally, patients and family members were invited back to the unit for follow up where they could discuss their experiences. Semi-structured

interviews with patients occurred at 3 to 6 months post ICU discharge, at which point patients had already received their diary and attended at least one follow up appointment with the option to return for further support if required. Therefore, the potential risk associated with diaries was already being managed by the clinical team providing this nursing intervention.

In addition to assessing potential risks to participants, it was important to consider risks to the researcher. Rubin and Rubin (2012) acknowledge that interviewing can be emotionally and physically exhausting for the researcher and it is important that they find ways to deal with this. As the research was conducted part-time over a period of 17 months the interviews were spaced out, however trying to organise these in between working 2 or 3 days a week in another health board and keeping up to date with transcribing completed interviews was challenging.

Managing distress

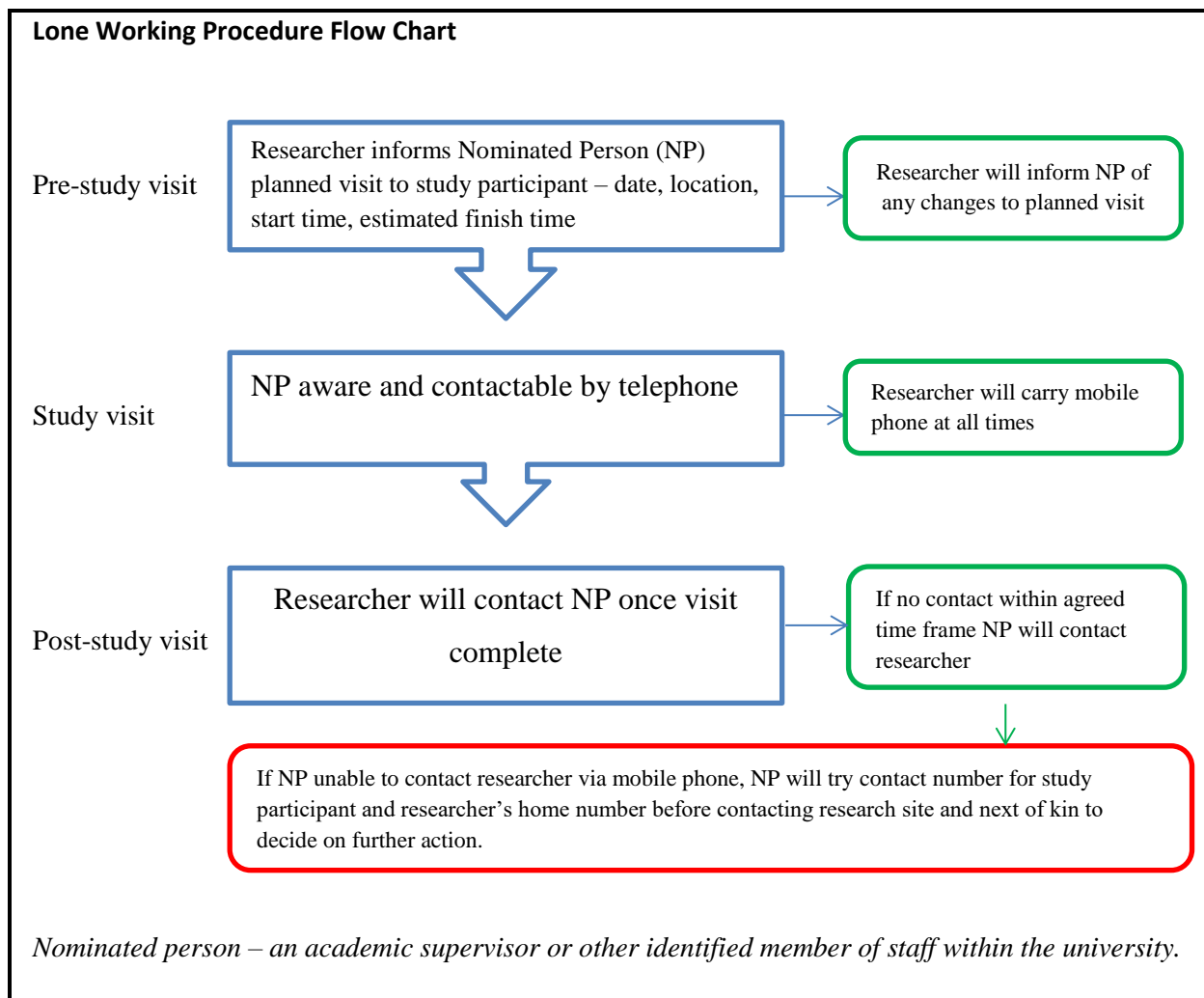
Participants who become distressed whilst taking part in any aspect of the research process will be managed in the following way.

- If it becomes apparent to the researcher that a participant is distressed, the researcher will pause and give the participant the option to discontinue whatever research activity is being performed.
- The researcher, within the limitations of her role, will reassure the participant and if necessary offer advice or refer onto the appropriate service. Permission from the participant will be sought before a referral is made, unless the researcher believes that the participant is at risk.
  - **Family members** will be advised to contact their GP if they require further help. It may also be appropriate, with their permission, to inform the nurse at the bedside caring for their relative.
  - **Patients** will be referred onto the critical care follow up service or advised to contact this service, which is available for all those who are eligible to take part in the study. They will also be advised to contact their GP and discuss this with their family if appropriate.
  - **Nurses** will be asked if they would like the researcher to inform a work colleague on shift and will be advised to follow this up with either occupational health or their GP if they require further support and referral onto another service.

*Figure 10: Managing distress*

Holloway and Wheeler (2010) have identified the safety of the researcher as a key ethical concern in undertaking interviews. They highlight the importance of supporting the emotional well-being of researchers when dealing with sensitive topics and putting measures in place to protect the researcher's safety when interviewing participants in the home. Fortunately, the researcher was already familiar with working in an ICU environment and communicating with patients and family members during and after the time in ICU. Furthermore, a close support network surrounded the researcher in the form of work colleagues and the researcher's supervisors who were not connected with the research site and therefore it was possible to confide in them without compromising confidentiality or anonymity of research participants. It was anticipated however that some interviews would be conducted in participants' own homes meaning that the researcher would be visiting these participants on her own. Therefore, a lone working procedure was

created and included in the study protocol to minimise the risk of carrying out such visits and to ensure the researcher's safety when visiting study participants outside the hospital setting, see Figure 11.



**Figure 11: Lone working procedure**

While it was possible to anticipate potential risks to both research participants and the researcher prior to the study starting, a further issue arose which the researcher did not expect, relating to the timing of approaching family members in the ICU. The researcher had experience approaching family members in an ICU setting from her clinical role as a critical care research nurse, however this was with research studies involving patients only. After approaching a few family members in the ICU for the current study it became apparent that some family members found it difficult

to take on board the possibility of participating in research themselves during this time. One family member became very tearful whereas on returning to another family member their loved one had deteriorated and later died. Any planned approach was discussed with clinical staff caring for the patient and their family. However, the researcher did not want to upset or cause any further stress to family members during this difficult time and yet it was important for the study to try and recruit complete triads. Therefore, waiting until patients had improved and were likely to survive before approaching their family members, which happened either in the ICU or on the ward after ICU meant the researcher intentionally avoided an action that may have caused harm (Beauchamp & Childress, 2013).

### 3.6.3 Beneficence

The principle of beneficence means

*“...to act for the benefit of others.” (Beauchamp & Childress, 2013, p. 203)*

If there is no expected benefit to ‘others’, including the individual and wider society, it is unethical to involve people in the research (Gelling, 1999). Furthermore, benefits should be greater than the risks in research (Holloway & Wheeler, 2010). While there was no direct benefit to individuals taking part in the research it has been suggested by Rubin and Rubin (2012) that having the opportunity to discuss experiences in an interview may be beneficial to the participant. This research gave participants the opportunity to discuss their experiences and views on critical care diaries. However, the main justification for carrying out the research was to gain an understanding of different people’s experiences with critical care diaries, thus adding to the current knowledge base and informing practice. Without further research into this area, especially on understanding how critical care diaries are experienced and used at different times in the critical illness journey and by those who are involved in creating and reading them, a potentially beneficial nursing intervention may never become available for those who may need it the most. Therefore, it was anticipated that participation in the research may help to improve services provided for future patients and their family members and thus benefit the wider society.



The principles of beneficence and non-maleficence are closely linked and often presented together. While non-maleficence is defined as doing no harm, the principle of beneficence involves taking measures to prevent and remove harm as well as doing good (Gelling, 1999; Orb, et al., 2001). Some of this discussion has already taken place in the previous section on non-maleficence therefore the remaining focus of this section will be on acting in a way that promotes good ethical research practice, for the benefit of others.

The researcher had up to date training in Good Clinical Practice (GCP) at the time of undertaking the research. Although relating mainly to clinical trials GCP training is a mandatory requirement of all researchers conducting research in the NHS.

Working as a research nurse in critical care, the researcher had significant experience in complying with GCP, which has been defined as

*“...an international ethical and scientific quality standard for designing, conducting, recording and reporting trials that involve the participation of human subjects. Compliance with this standard provides public assurance that the rights, safety and well-being of trial subjects are protected, consistent with the principles that have their origin in the Declaration of Helsinki, and that the clinical trial data are credible.”*  
<http://ichgcp.net/introduction> accessed on 4th June 2017

As a research nurse, the researcher was employed as part of the clinical team in critical care whereas taking on the role of nurse researcher in a different NHS trust to her own meant that the researcher was not involved in providing any direct clinical care to patients and their families, or involved in any clinical decision making. Staff were made aware of the researcher's previous experience and her role as a nurse researcher prior to starting the research and throughout her time in the practice setting. It was made clear that while the researcher would not be involved in providing care to patients and their families she was a registered nurse with significant experience in this environment and if any practice was observed that may cause harm or put people at risk this would be raised firstly with the person involved and if necessary reported to a member of staff in a position of authority, in line with the Nursing and Midwifery Council (NMC) professional code of conduct (NMC, 2015).

Fortunately, there was no mal-practice observed. However, there was one occasion where the researcher had to inform a member of nursing staff about a patient who had disconnected the oxygen tubing from their tracheostomy. The researcher observed on the main monitor at the nursing desk that a patient's oxygen saturation was dropping, with cardiovascular compromise and noticed that there was no one near the bed space. On identifying and informing the nearest nurse that there was a problem, the researcher was told by that nurse that she was not looking after that patient. However, the researcher, having recognised the seriousness of the situation challenged the nurse who immediately attended to the patient. This situation created an ethical dilemma for the researcher as in her own ICU she would have attended to this patient herself if no one else was available whereas access to this unit was granted based on the understanding that the researcher would not be involved in clinical care. On reflection, this was a potentially life-threatening situation which the researcher had the knowledge and skills to deal with and was prepared to step in if no action was taken by others responsible for the patient. The researcher's actions and thought process were in keeping with the NMC Code of *Professional standards of practice and behaviour for nurses and midwives* which must be upheld by all nurses and midwives

*"...whether they are providing direct care to individuals, groups or communities or bringing their professional knowledge to bear on nursing and midwifery practice in other roles, such as leadership, education or research." (NMC, 2015, p. 2)*

Therefore, in addition to the principles of GCP the researcher as a nurse had an obligation to act in line with her professional code of conduct throughout the research process.

### **3.6.4 Justice**

The final ethical principle to be addressed in relation to this research is the principle of justice. Beauchamp and Childress (2013) discuss the various theories of justice and note that in relation to research and healthcare one of the main issues is around fair access. This is in addition to treating people fairly and not exploiting vulnerable groups (Beauchamp & Childress, 2013), which Gelling (1999) highlights include any potential participants in a healthcare setting. The issue of fair access came to the

forefront in the 1990's in response to patients with HIV/ AIDs and access to new treatments whether as part of research or not. This prompted a change in the ethical assessment of studies to consider the potential benefits of participating in research as well as trying to protect patients from harm and exploitation (Beauchamp & Childress, 2013).

While the principle of justice is concerned with being equal and fair Orb et al (2001) note that in qualitative research one way of implementing this principle is by

*“...listening to the voices of the minority and disadvantaged groups as well as protecting those who are most vulnerable, such as children, prisoners, the mentally ill, and the elderly” (p. 96)*

The researcher made the decision to exclude prisoners, those under the age of 16 (children in Scotland) and those who did not have the mental capacity to participate in the informed consent process. While a conscious effort was made to include a diverse sample, as outlined in section 3.5.4, it became apparent that it was difficult to recruit male family members, which will be discussed in more detail in the findings and discussion chapters of this thesis. On a more practical level, with regards to fair access, the researcher offered home visits for interviews with patients and family members to make participation possible for those who were unable or did not wish to return to the hospital.

Finally, the ethnographic approach requires the researcher to identify any biases they may bring to the research and emotional responses from their experiences as these may affect the observations and interpretations they make (Roper & Shapira, 2000). A reflexive diary was kept to record emotional responses to events and people as well as decisions made throughout the research process, which in addition to highlighting any biases the researcher had made it possible to identify and review decisions around sampling and data collection.

### **3.7 Trustworthiness**

The criteria used to assess the 'goodness' or methodological and analytical quality of qualitative research are based on the concept of trustworthiness, introduced by Lincoln and Guba in their seminal book *Naturalistic Inquiry* (Lincoln & Guba,

1985). Referred to as the Trustworthiness criteria, these were developed in parallel and as an alternative to the conventional or positivist criteria of internal validity, external validity, reliability and objectivity (Lincoln & Guba, 1985). Whereas, the trustworthiness criteria include credibility, transferability, dependability, and confirmability. Each of the trustworthiness criteria will be introduced, followed by discussion around the strategies taken by the researcher to meet these criteria. However, to begin with an overview of the decision to use the trustworthiness criteria will be presented as there are different perspectives on how qualitative research should be judged, as highlighted by Holloway and Wheeler (2010).

The trustworthiness criteria have been well received and are widely used in qualitative research (Appleton & King, 1997). However, one of the major criticisms discussed openly by Guba and Lincoln is that the criteria were developed from concerns relevant to the positivist paradigm (Lincoln, 1990; Guba & Lincoln, 1994). Guba and Lincoln (1989) note that although adjustments were made to accommodate the naturalistic paradigm

*“...there remains a feeling of constraint, a feeling of continuing to play “in the friendly confines” of the opposition’s home court.” (Guba & Lincoln, 1989, p. 245)*

Furthermore, they recognise that the criteria are primarily concerned with methods and therefore, do not account for other important factors such as the outcome or product of the research, stating that

*“...prolonged engagement and persistent observation (or any other methods one might choose) do not ensure that stakeholder constructions have been collected and faithfully represented.” (Guba & Lincoln, 1989, p. 245)*

Thus, the extent to which different realities are represented might be questioned.

In response to their critics and their own dissatisfaction with the trustworthiness criteria, Lincoln (1990) describes how an additional set of criteria, grounded in the basic assumptions of constructivism and referred to as the Authenticity criteria were developed. The authenticity criteria consist of fairness, ontological authenticity, educative authenticity, catalytic authenticity and tactical authenticity (Guba &

Lincoln, 1989). These criteria, in contrast to the trustworthiness criteria, are said to demonstrate how authentic the research is, for example, in representing participant's ideas however, they have not been as popular in qualitative research as the trustworthiness criteria (Holloway & Wheeler, 2010).

The trustworthiness criteria have been selected in this research as it appeared from the researcher's understanding of the authenticity criteria that they were not appropriate and the researcher was less familiar with these criteria. The primary aim of the research was not to help participants understand their social world, improve their understanding of others or influence their decision making and empower them, which appear to be fundamental in meeting the authenticity criteria as outlined in Guba and Lincoln's (1989) book *Fourth Generation Evaluation*. However, it is anticipated that new insight into the experiences of critical care diaries will be offered so in a broader sense authenticity might be achieved in the research with a wider audience, so for example the reader or future patients, family members and nurses who interact with critical care diaries. Nevertheless, the researcher would like to acknowledge that the authenticity criteria did open her mind to other ways in which qualitative research can be assessed and regardless of the criteria selected a range of strategies exist that qualitative researchers can draw upon to demonstrate and ensure the quality and trustworthiness of their research (Holloway & Wheeler, 2010). The trustworthiness criteria of credibility, transferability, dependability and confirmability will now be outlined and the strategies used by the researcher to address each of these discussed.

### 3.7.1 Credibility

Credibility is concerned with the researcher being able to demonstrate that participants' views (multiple constructions) have been adequately represented and the findings and interpretations (reconstructions) are

*"...credible to the constructors of the original multiple realities."*  
(Lincoln & Guba, 1985, p. 296)

The researcher allocated 18 months in the research process for recruitment and data collection at the site. This was on a part time basis however represented significant

prolonged engagement which has been identified as an activity supporting the likelihood of credible findings being produced (Lincoln & Guba, 1985). This added to the researcher's understanding of the experiences of critical care diaries as well as being able to build trust and rapport with participants and potential participants in this environment. Building trust and rapport in this way

*"...makes it more likely that useful and rich information will be obtained." (Polit & Beck, 2013, p. 326)*

Through time, nurses working in the ICU accepted the researcher as a visiting member of their team. Whereas family members who often spent days or weeks visiting in the ICU became familiar with the researcher being around, whether they were eventually approached and decided to participate or not. Patients learned about the researcher from their family members or from nurses working in the ICU when they were in the ward or returned to the ICU for their follow up appointment.

Triangulation of data and methods was used to explore experiences of diaries from different perspectives and is another strategy that can add to credible findings being produced (Lincoln & Guba, 1985). Triangulation of data was achieved through person triangulation by exploring diaries from the perspectives and experiences of patients, family members and nurses. Additionally, it could be argued that time triangulation, another form of data triangulation (Polit & Beck, 2013), was achieved as interviews with nurses and family members were performed at a different time to patients, thus providing insight into diaries during and after the time in ICU.

Whereas triangulation of methods involved using multiple methods of data collection through observations, semi-structured interviews and examples of diary entries. Polit and Beck (2013) note that triangulation enables the researcher to gain a comprehensive picture of the phenomenon being studied within the context where it occurs. Furthermore, it allows findings to be checked against one another so, for example, in this research it was possible to compare and check between different members of a triad, different members of each group and between groups.

Finally, discussion around the strategies adopted to achieve credibility would not be complete without considering member checking. Member checking is the process

*“...whereby data, analytic categories, interpretations, and conclusions are tested with members of those stakeholding groups from whom the data were originally collected...” (Lincoln & Guba, 1985, p. 314)*

Lincoln and Guba (1985) suggest that member checking is one of the most important techniques that can be used to establish credibility, it can be done formally or informally and is a continuous process.

Informal member checking was carried out during interviews with participants through deliberate probing and summarising, or repeating information back to participants. This helped to ensure the researcher understood what participants were telling her. After each observation, there was an opportunity to discuss with the nurse what happened during the diary related activity. The researcher explained what she observed and discussion followed from there. However, more formal methods of member checking were not used in this research. For example, participants were not given interview or observation transcripts or summaries of their interviews to review and make changes.

In keeping with a constructivist epistemology, knowledge (data) was co-constructed by the participant and the researcher. However, it could be argued that the co-construction of knowledge should continue throughout the research process, including analysis of data and writing of the research report. The main reason for not engaging in formal member checking was due to concern around participants' perceptions and experiences of diaries changing through time as well as having to re-visit experiences of critical illness which might be upsetting. In this research, it was important to interview nurses and family members close to the time the patient was in ICU, as this is when they are involved in using the diary. Perceptions changing through time is a recognised issue with member checking (Holloway & Wheeler, 2010). Further issues with member checking include a difference between researcher and participant perceptions, participants reacting in a defensive way, participants being unable to develop a critical viewpoint from having a close relationship with the researcher or they believe the researcher is more knowledgeable than them (Holloway & Wheeler, 2010; Polit & Beck, 2013). Furthermore, it is acknowledged that researchers take data to a more abstract theoretical level, which although

grounded in individual participants' perspectives moves beyond this and includes multiple perspectives (Holloway & Wheeler, 2010).

### 3.7.2 Transferability

Transferability relates to being able to transfer the findings or 'working hypotheses', which are time and context dependent, to other similar situations (Lincoln & Guba, 1985). Transferability therefore depends on the researcher providing adequate detail so that a judgement can be made on the similarity of other situations and thus whether the findings are transferrable or not (Topping, 2010). The main technique used by researchers to achieve this is through thick description (Guba & Lincoln, 1989), which requires prolonged engagement in the research setting (Holloway & Wheeler, 2010), see previous section 3.7.1. However, it is up to the reader to make their own judgement or evaluation of the extent to which the findings are transferrable (Lincoln & Guba, 1985). Thick description is provided throughout this thesis. For example, the process of collecting data and analysis have been presented in detail therefore providing a transparent record of the methods used, made possible through keeping comprehensive field notes documenting data collection. Additionally, the field notes helped to inform the analysis and write up of the research findings presented in the following chapter.

### 3.7.3 Dependability

Dependability is concerned with the stability of data over time (Guba & Lincoln, 1989). Lincoln and Guba note that dependability involves

*"...taking into account both factors of instability and factors of phenomenal or design induced change." (Lincoln & Guba, 1985, p. 299)*

These are likely to occur as the research progresses and evolves in relation to the context where it is undertaken. Therefore, it is important that the researcher is transparent about the research process and any decisions made (Topping, 2010), so that those not involved in the process can understand what happened. This chapter has provided a detailed account, or audit trail, of decisions made before and during the research as well as describing the research process (Holloway & Wheeler, 2010). Lincoln and Guba (1985), who are said to be responsible for developing this concept



(Holloway & Wheeler, 2010), note that an audit trail can be examined to determine if the process and the product of the research are acceptable. The process of the research is associated with dependability whereas the product of the research is associated with confirmability, introduced in the following section 3.7.4.

### 3.7.4 Confirmability

Confirmability, the final of the trustworthiness criteria, is about ensuring that the data, findings and interpretations are

*“...rooted in contexts and persons apart from the evaluator and are not simply figments of the evaluator’s imagination.” (Guba & Lincoln, 1989, p. 243)*

The term evaluator can be taken to mean researcher and to achieve confirmability the researcher must be able to demonstrate to the reader that the product of the research has been established from the data (Lincoln & Guba, 1985). As introduced already an audit trail can provide the reader with the necessary detail to make a judgement on the acceptability of the product or in other words, findings of the research. In addition to the audit trail, peer debriefing (Lincoln & Guba, 1985) was undertaken with the researcher’s supervisors throughout the period of data collection and analysis, extending into writing up the findings. This included presenting raw data such as interview transcripts, reviewing the emerging codes and categories or themes and the researcher’s interpretations of the data. Notes were written up by the researcher from each session thus adding to the audit trail. Furthermore, peer debriefing is another technique useful in establishing credibility of the research (Lincoln & Guba, 1985).

## 3.8 Chapter summary

This chapter has discussed in detail the research design and methods selected for this research. The research design included an overview of the theoretical position underpinning the research, followed by an introduction to ethnography as a qualitative research approach and in relation to healthcare and nursing research. The researcher’s early thoughts on how ethnography fitted in with the research aim and

questions were stated, before identifying focused ethnography as the most suitable qualitative approach.

Moving on from this, the methods used to conduct the research were outlined, starting with an overview of how the research setting was selected and what steps were taken to gain access, both informal and formal. Sampling strategies including the plan to recruit patients, nurses and family members as triads were outlined and presented alongside the inclusion and exclusion criteria. The data collection techniques of semi-structured interviews, supplemented with focused observations and photographs of diary entries were considered with attention given to how this data was managed in preparation for data analysis. The process of data analysis, using a thematic analysis approach, was summarised with Braun and Clark's (2006) Six Phases of Thematic Analysis and discussion around how the QDAS NVivo version 9 was used as a tool to assist in this process. Ethical considerations of the study were framed using Beauchamp and Childress' (2013) four moral principles of respect for autonomy, non-maleficence, beneficence and justice. Finally, an overview of the measures taken to ensure trustworthiness of the study were guided by Lincoln and Guba's (1985) Trustworthiness Criteria.

Throughout the process of designing and conducting the research, reported in this chapter, the researcher kept a reflexive diary. This enabled the researcher to reflect on and share decisions made, at different stages in the research process with her supervisors and now a wider audience through writing this chapter. It is hoped that this level of detail and transparency will enable the reader to understand clearly why the research was conducted in this way and how the findings were generated, which will be presented in the next chapter.



## Chapter 4 Findings

### 4.1 Introduction

This chapter will present an overview of key findings from the research study.

Findings will be presented as themes and sub themes, identified from analysing the study data. Each theme will be described and the associated sub themes introduced to the reader. Quotes from study participants will be used to illustrate the findings along with diary excerpts and narrative from the researcher in first person where appropriate.

The main content of the data was generated through interviews with participants. However, as outlined in the Research Design and Methods chapter there were different elements to the data gathered, including focused observations of nurses carrying out diary related activities, informal discussion with nursing staff and examples of diary entries which were taken from diaries belonging to the patient participants interviewed. Diary entries will appear as photographs with the description and source listed next to the figure number underneath the photograph. Fieldnotes will appear in black italic text indented from the main paragraph.

Quotes from participants will be used as the main source of data in the findings chapter. All quotes have been indented from the main paragraph in italics and colour coded **blue for nurse quotes**, **green for family member quotes** and **purple for patient quotes**, to help the reader distinguish between the participants. Each participant has been given a pseudonym appearing in brackets after the quote and followed by N for nurse, FM for family member and P for patient. The number next to this letter indicates the group or triad each participant belongs to so for example Angela FM1 and John P1 are related and Jane N1 was a nurse who had been involved in their care during the time in ICU. Details of the participants interviewed are outlined in Table 6 and Table 7.

*Table 6: Family member and patient participants*

Family member participants	Age	Relationship to Patient	Patient participants	Age	Type of admission	Length of critical care stay
Angela (FM1)	50	Wife	John (P1)	58	Emergency surgical	25 days
Heather (FM2)	48	Wife	Steven (P2)	50	Elective surgical	10 days
Lynn (FM3)	44	Daughter in law	<b>No consent. Died &lt;3 months post ICU discharge.</b>			
Katrina (FM4)	31	Daughter	Alison (P4)	53	Emergency medical	9 days
Mary (FM5)	67	Wife	<b>No consent. Interview arranged, cancelled due to family circumstances.</b>			
Jean (FM6)	59	Wife	Graham (P6)	53	Emergency surgical	27 days

*Table 7: Nurse participants*

Nurse participants	Age	Role	Critical care experience
Jane (N1)	36	Staff nurse & diary team member	12 years
Carrie (N2)	24	Staff nurse	3 ½ years
Valerie (N3)	50	Staff nurse	25 years
Beth (N4)	30	Staff nurse & informal diary team support	11 years
Fiona (N5)	42	Staff nurse	12 years
Jim (N6)	44	Charge nurse	23 years

The five main themes presented in the findings chapter are Information, Communication, Emotion, Person centered and Gender. Information relates to the information contained in the diary and findings relating to this are discussed in terms of the content, presentation and interpretation of information. Communication explains the different ways in which diaries were used to communicate, extending beyond the basic provision of information for patients after ICU and including presence, facilitation of communication and communication through the diary. Emotion is about the emotion present in the diary and experienced from interacting with the diary whether that is through writing in it or reading it, explained as emotional effort, emotional support and attachment to the diary. Person centered relates to how diaries promote a more personal individualised approach to caring for patients and family members experiencing critical illness and is discussed through the diary as part of care, making an effort and identity. Finally, the theme Gender starts with discussion around male family members and diary use in the ICU and then introduces other factors such as age and level of literacy. An overview of the themes and sub themes identified from the analysis of the data is provided in Table 8.

*Table 8: Themes and sub themes from the analysis of data*

Themes	Sub themes
1.2 Information	1.2.1 Content of information 1.2.2 Presentation of information 1.2.3 Interpretation of information
1.3 Communication	1.3.1 Presence 1.3.2 Facilitating communication with the diary <ul style="list-style-type: none"> <li>▪ 1.3.2.1 Communication during the time in ICU</li> <li>▪ 1.3.2.2 Communication after the time in ICU</li> </ul> 1.3.3 Communication through the diary <ul style="list-style-type: none"> <li>▪ 1.3.3.1 The unspoken word</li> <li>▪ 1.3.3.2 Communication in relationships</li> </ul>
1.4 Emotion	1.4.1 Emotional effort <ul style="list-style-type: none"> <li>▪ 1.4.1.1 Family member's emotional effort</li> <li>▪ 1.4.1.2 Patient's emotional effort</li> <li>▪ 1.4.1.3 Nurse's emotional effort</li> </ul> 1.4.2 Emotional support <ul style="list-style-type: none"> <li>▪ 1.4.2.1 Emotional support through writing in the diary</li> <li>▪ 1.4.2.2 Emotional support through reading the diary</li> </ul> 1.4.3 Attachment to the diary
1.5 Person centered	1.5.1 Diary as part of care 1.5.2 Making an effort 1.5.3 Identity
1.6 Gender	N/A

## 4.2 Glossary

As outlined in section 3.5.6 of the methods chapter some quotes presented in this chapter contain Scots words and abbreviations as spoken by participants. These have been listed for reference in Table 9.

*Table 9: Glossary of Scots words, abbreviations and other words spoken by participants*

<b>aboot</b> – about <b>afore</b> - before <b>ah</b> - I <b>am</b> - I'm <b>an</b> - and <b>av</b> - I've <b>aw</b> - all <b>aye</b> - yes <b>bamboozle</b> - confuse <b>binned</b> - thrown away <b>birling</b> - going round and round <b>blethering</b> - talking nonsense, long winded conversation <b>cannae</b> - can not <b>cause</b> - because <b>couldnae</b> - could not <b>couried in</b> - tucked in, cosy <b>dae</b> - do <b>didnae</b> - did not <b>dinae</b> - do not <b>doesnae</b> - does not <b>doon</b> - down <b>dunno</b> - do not know <b>d'you</b> - do you <b>fae</b> - from <b>fricken</b> - substitute for a swear word <b>gee them on</b> - encourage <b>gonna</b> - going to <b>grandkids</b> - grandchildren	<b>hen</b> - term of endearment usually addressed to a female <b>highflalutin</b> - complicated <b>hinging</b> - hanging <b>intae</b> – into <b>it'd</b> – it would <b>kids</b> - children <b>kin</b> - can <b>kinda</b> - kind of <b>ma</b> - my <b>mind</b> - remember <b>nah</b> - no <b>noo</b> - now <b>oot</b> - out <b>oor</b> - our <b>ratty</b> - feeling irritable <b>reeling</b> - in a state of shock or anger, wound up <b>tae</b> - to <b>telt</b> – told <b>the day</b> - today <b>wanna</b> - want to <b>wasnae</b> - was not <b>werena</b> - were not <b>wouldnae</b> - would not <b>wee</b> - little <b>woulda</b> - would have <b>windae</b> - window
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## 4.3 Information

Diaries in this setting were created and co-authored by nurses and family members for patients to use during their recovery, providing the patient with information about their time in the intensive care unit (ICU). The theme information relates to information contained in the diary, frequently referred to by participants when talking about their experiences with diaries. Therefore, to give the reader insight into information contained in diaries created in the participating ICU and provide context for the following sections in the findings chapter, the theme information will be discussed.

Three sub themes were identified in the theme information: *content of information*; *presentation of information* and *interpretation of information*. Content of information gives an overview of the contents of the diary as discussed by participants. Presentation of information relates to the language and structure of diary entries and how events are translated into the diary for the patient to read at a later date. Interpretation of information gives insight into how participants view the information contained in the diary and what this means to them.

### 4.3.1 Content of information

The content of information in the diary was frequently referred to by participants when talking about their experiences with diaries. An overview of the participants' views of the content will be presented to inform the reader of the types of information that can be found in a critical care diary.

The diary was started by nursing staff in the ICU after the patient was admitted. The first entry was written by the nurse caring for the patient when the decision had been made to start a diary, one nurse explains this further.

*...why they were here, why they were in that situation, what we were doing now em and that their family were, they were here and you know we were keeping them up to date. (Valerie N3)*

On the following page, there is an example of a 'first' diary entry written by a nurse in the ICU.

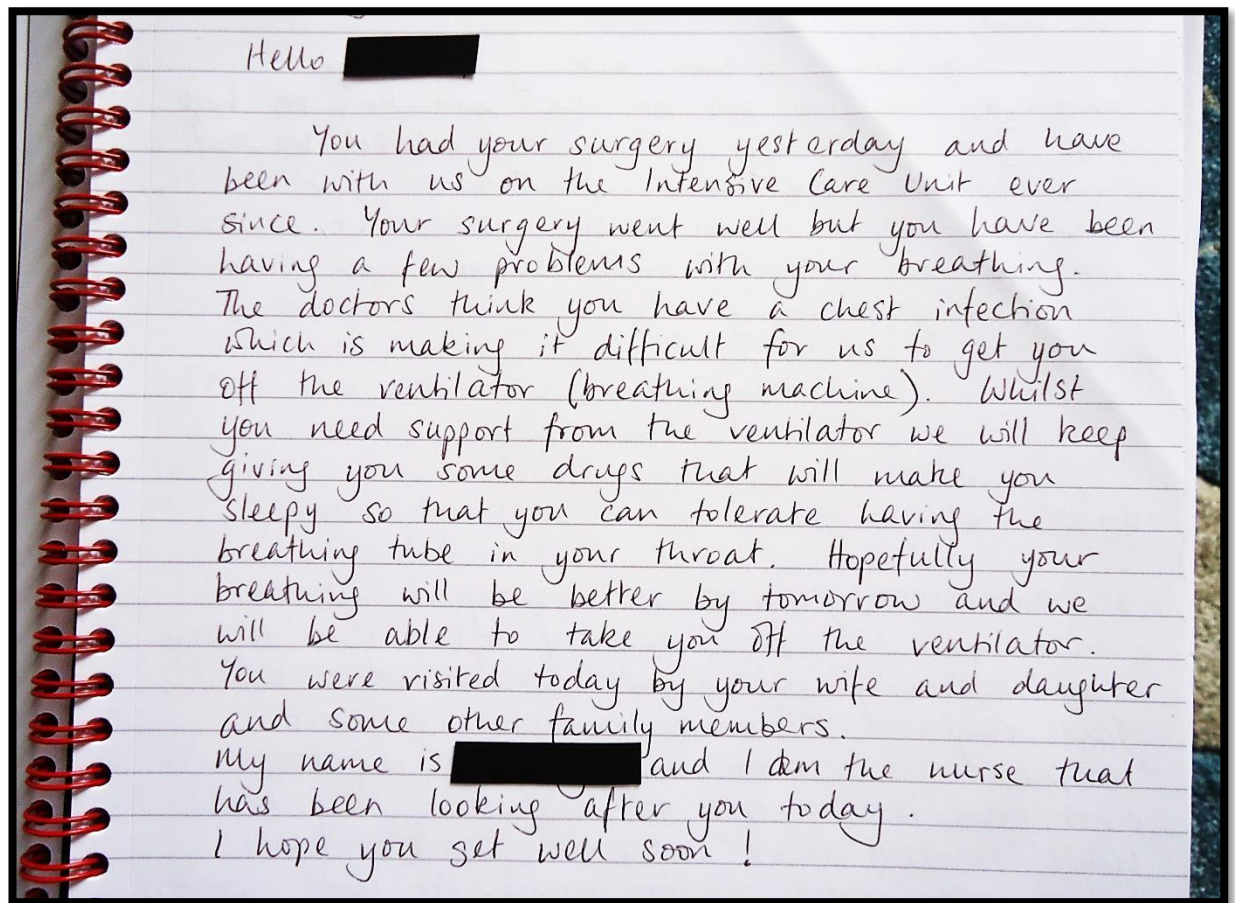


Figure 12: Nurse 'first' diary entry - P2

Nurses continued to write in the diary for the patient while they were in the ICU, updating it on a regular basis and explaining what was happening.

*If am using the diary ah basically would write an excerpt in, just a wee summary of the patient's day and how they've been. Just something that they would read in the future to let them know how they were that day. You know 'hello nice to see you opened your eyes for a couple of minutes, ah had a wee chat with you, your wife was in, we talked to you about various things'. That, that's the sort of thing you write just so that they know that "Oh that day ah was starting to wake up". 'We've reduced your sedation, you're waking up and we've explained to you, you might feel a little bit frightened', just things like that. (Jim N6)*

How the patient was responding, the progress they were making and conversations arising with the patient and their family during visiting or on the phone were recorded by nursing staff in the diary, as seen in the following diary excerpt.

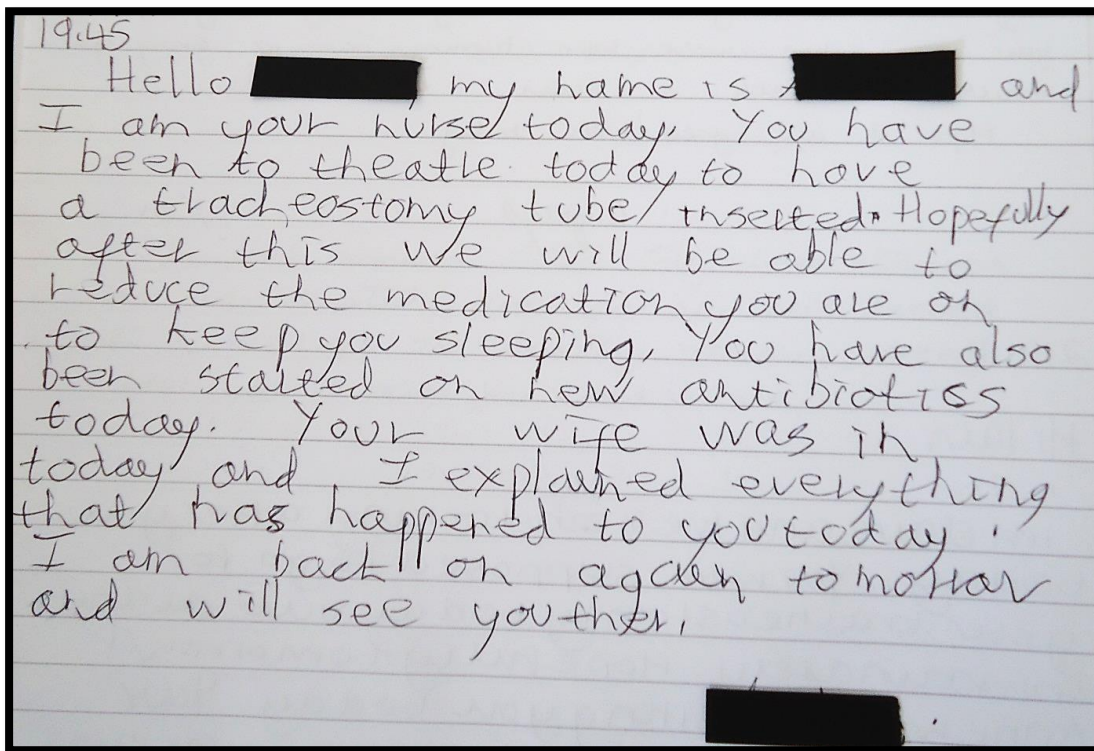


Figure 13: Nurse 'daily' diary entry - P6

Furthermore, nurses thought it was important to write about the environment and events that patients may be able to relate to later on especially those involving the senses, sensory experiences.

*...if av been night shift and they've been awake ah write in 'the birds started singing at five o'clock this morning and we were listening to them' and silly things like that. Things that they can hear, not necessarily see. Or 'you're hot, we had your heated blanket on overnight cause you were really cold and we had you all covered in...' an things like that. (Fiona N5)*

Fiona believed that hearing certain noises or being aware of changes in temperature were things that patients were likely to remember from their time in ICU. The physical interactions nurses performed with patients such as moving the patient to change their position or assisting with personal hygiene and comfort were recorded in the diary too.



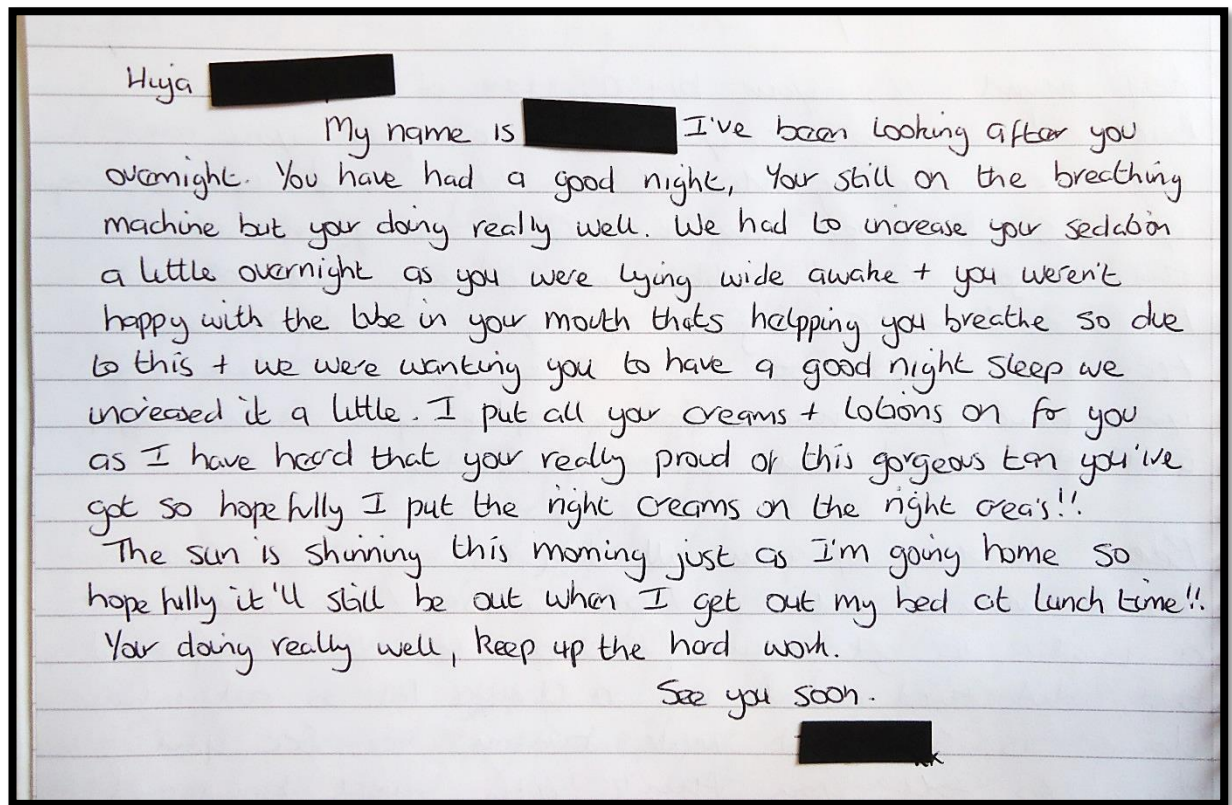


Figure 14: Nurse 'interaction' diary entry - P4

Family members were encouraged by nursing staff to write in the diary while they were visiting the patient in the ICU. Nurses invited family members to write about what they were thinking and feeling, what had been going on at home and anything else they thought the patient would be interested in reading.

*We used to just put in things we done at work, different things through the day and what the weather was like. 'Oh the boys put the silage in the day' an you know they things that she'd probably think 'God'. You know cause that was like a week probably that she's missed. (Lynn FM3)*

Family members who were unable to visit, for example young children, were encouraged to contribute to the diary. Any content brought in by family members such as letters, get well cards or drawings were placed in the diary by nursing staff alongside the daily entries.



*Figure 15: Family member 'child's drawing' diary entry - P4*

Recording what had been happening on a daily basis, whether from home or with the patient in the ICU, was referred to by participants as 'day to day' things or information.

*...ah just explain it as a book, you know it's for them (family members) to record what's happening day to day so that their relative knows what's been happening day to day. (Jane N1)*

In addition to the 'day to day' information contained in the diary some family members wrote about their thoughts and feelings, encouraged by nursing staff as mentioned earlier.

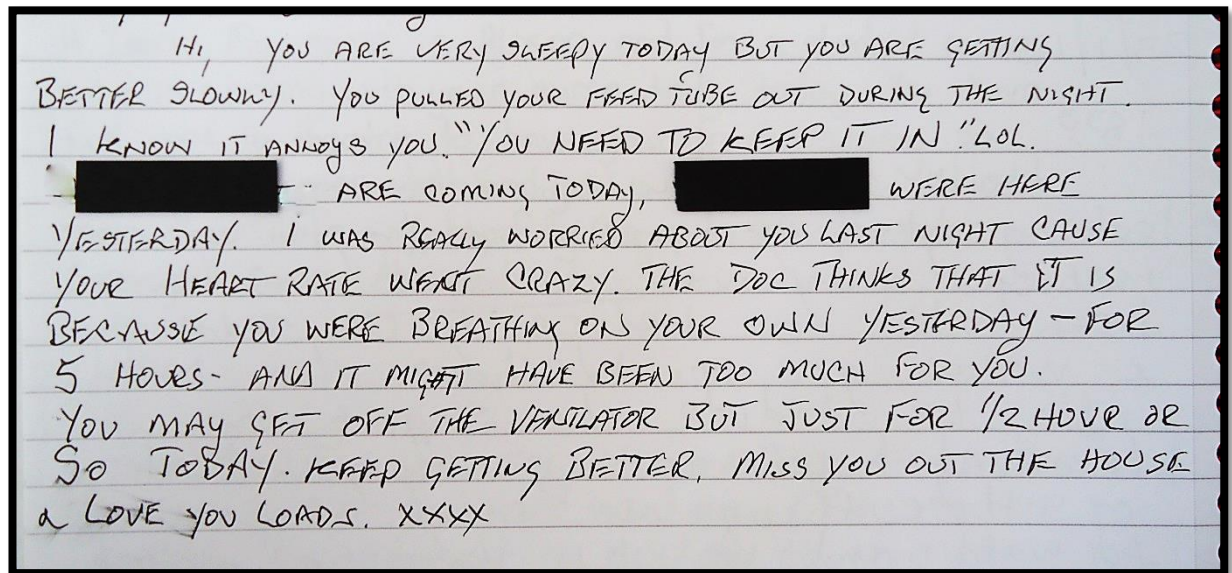


Figure 16: Family member 'thoughts and feelings' entry - P6

Reading about close family member's thoughts and feelings gave patients an insight into what their family was going through during that time.

*...a good bit oh the diary is their thoughts an what they've went through tae a certain degree. The, the state ah was in and eh (pause) different things ah went through before ah woke up they went through it with me, not physically but they went mentally through it. (John P1)*

Family members read information contained in the diary too. Mostly the information they found in the diary they knew about already from nursing staff.

*We knew, and sometimes we even knew before they had written it in the diary (laughs). (Mary FM5)*

However, one family member found information in the diary she did not know about, unexpected information.

*A couple of times when ah phoned during the night they just said he'd had a peaceful night, which he obviously did do. Then you'd go up the next day an you'd see the wee bit in 'you'd a peaceful night Steven but your heart was racing slightly'. Obviously they don't tell you that on the phone tae worry you because they don't see it as a concern, but obviously when you see it in the diary...ah says to her so "why was his heart racing?". But it was one of the complications of the surgery, they've got it well sorted now. (Heather FM2)*

Patients generally did not know what they would find in the diary.

*...ah didn't know what to expect. (John P1)*

Even patients who were aware of a diary being kept were unsure what they might find in the diary.

*...ah suppose ah had an idea what was in it...or did ah? Ah don't know...ah really don't know. The kids had told me they were writing in it...but did ah know what they were writing...no ah think ah probably just assumed that they were writing about me...an about themselves...ah don't know. (Alison P4)*

From observing the process of the diary being handed over to patients after ICU by a nurse from the diary team, time was spent explaining to patients what they might find in their diary, as detailed in the following excerpt from one of the focused observations performed by the researcher.

*Nurse spoke about some of the effects of being in ICU which was mainly prompted by the patient's experiences and questions. Nurse explained might not remember much, this is quite normal. The diary can sometimes help people put the pieces back together and fill in the gaps. Some patients find the first page useful as it tells them about coming into ICU and why. Patients often don't remember much about this and some can't even remember coming into hospital. (O-01 Diary Handover in Ward CM fieldnotes)*

As detailed, the process of handing over the diary included giving information on the experience of having been critically ill in ICU and to inform patients of the follow up service available. Reflection and informal discussion with the nurse after the activity



provided further insight into this interaction, with regards to the information about the contents of the diary.

*Although this activity has been described as handing over the diary to the patient in the ward, this seemed to be the smallest part of the interaction and minimal information about the use of diaries was given for example how the patient might feel when they start reading it, what kind of things might have been written.*

*The nurse explained to me that she didn't tend to give too much information at this stage as patients aren't ready for it. (O-01 Diary Handover in Ward CM fieldnotes)*

Although most patients did not know what to expect in their diary this was different from family members finding unexpected information as family members were often reading the diary each time they visited the ICU, so had an idea of the type of information it contained.

The contents of the diary gave an overview of what happened during the time in ICU from a dual perspective of nurses and family members. Having a daily account of what was happening when the patient was in ICU was what made this document a diary.

*Calling it a diary is exactly what it is, it's a day tae day thing telling you what happened to you. (John P1)*

However, it was recognised by nurses, family members and patients that some information was not recorded in the diary which will be discussed further in the following section, 4.3.2 *Presentation of information*.

The main body of information contained in the diaries used by participants in this study was written by nurses, family members and close friends. However, two patients wrote in their own diary. For example, whilst still in hospital one patient explained

*...ah wrote things in myself just, just afore ah came oot, the last day ah think. (Steven P2)*



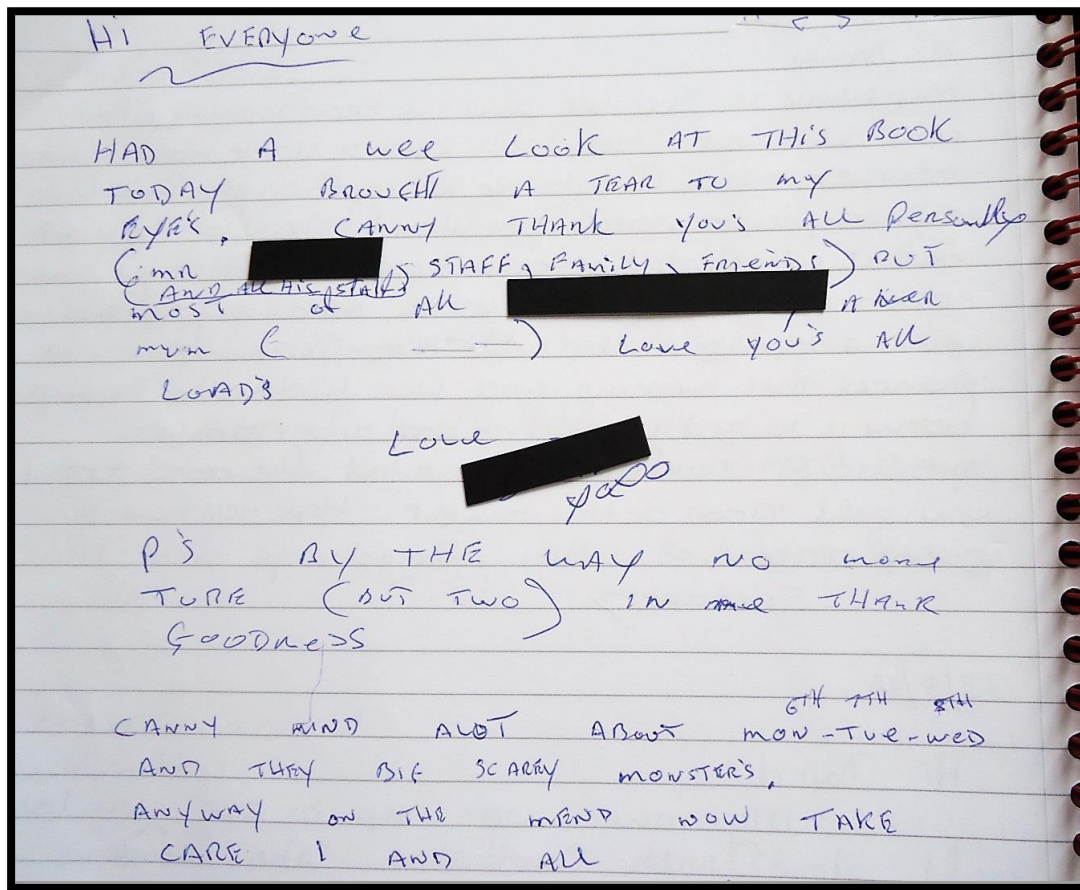


Figure 17: Patient's 'own' diary entry - P2

In summary, the information contained in the diary was written by nurses and family members. The first diary entry, written by nurses, contained information about the reason for admission to ICU. Following entries updated what had been happening and certain aspects of care given. Nurse entries often included evidence of communication with family members and information about the surrounding environment. Family members recorded what was happening at home and their thoughts and feelings. Those unable to visit the ICU, such as young children, were encouraged to contribute to the diary and did so through letters, get well cards and drawings. The diary was updated on a regular basis and information was referred to as day to day information.

Family members were updated by nursing staff in the ICU which meant that when they read the diary they already had an idea of what was going on. However, one

family member reported finding unexpected information in the diary. The information contained in the diary provided patients with a record of what happened during the time they were in ICU and what their family was going through. Patients generally did not write in the diary themselves in ICU however two out of the four patients reported writing in their diary after being in ICU.

#### 4.3.2 Presentation of information

The way that information was presented in the diary was raised mainly by the nursing staff who spoke about how they structured their diary entries, the type of language they used and how they wrote about events occurring in the ICU.

Nursing staff were very aware of the language they used in the diary and tried to avoid using ‘nurse’ or ‘medical jargon’ in preference for using ‘laymen’s terms’.

*...write it in a way that they'll understand. Not too much medical jargon. Just try and bring it down tae the basics and eh no highfalutin words, eh 'central lines' and things like that, you know just 'drips' and things like that. (Valerie N3)*

Family members appreciated nurses writing in this way as they were able to understand what was going on and believed that eventually their loved one would be able to read and understand this too.

*...they're putting it in a kinda clinical sense, but in a way that we understand and a way that John would understand it. (Angela FM1)*

Diary entries from nurses were written to the patient and were based on what had been happening with the patient on that shift.

Hi [redacted] my name is [redacted] and I have been looking after you today. You are doing really well. You are still on the breathing machine to help you but we are slowly reducing the support. You have had a very busy day, we have been back down to the CT Scanner to get a scan of your chest and then the doctors were trying to put in another chest drain but they had no luck. However you did not feel anything during this as we made you have a little sleep. They will try again tomorrow but I promise you won't feel a thing. Hope to see you looking better when I return on Friday night. Keep working hard [redacted] 😊

**Figure 18: Nurse 'what has been happening' diary entry - P1**

Nurses reported using a structure to help them think about what they were writing however they found themselves writing the same kind of things for patients, as often patients experienced similar events during their time in ICU.

*Ah think cause ah have a structure ah do kinda write the same things. Ah try, ah try and make it more personal to the person but you (sighs)...quite often or not our patients are doing the same things. They're like weaning of the ventilator, or they've had complications with their wound, or something. Like it's quite often the same kinda story but just trying to make it a wee bit different if you can. (Carrie N2)*

Thinking about what information was included and how information was presented or written was raised by both nurses and family members. Information or facts were grounded in the reality of the situation or events occurring however a version of this reality was recorded in the diary. For example, how the patient actually looked physically to their family was not necessarily what their family would write in the diary, as explained by one family member.

*You were writing what you wanted her tae be able tae read later on. You know an that was why ah didn't put 'you look like death warmed up the day, you look absolutely dreadful'. You know em because she wouldnae need tae read that. You know they (the family) all tell her that anyway (laughs). (Lynn FM3)*

Similarly, nurses wrote about what was happening based on what they thought might be of value to the patient later on.

*It's always in the back of your mind, you don't want to write stuff that was going to be of no value to them whatsoever because they'll be reading this after they've got better. You've got to have that in mind. Although, ah mean you can't go 'oh my god you've pulled your tube out you nearly died it was horrible, we couldn't get you intubated, your sats were 20%!' Ah mean you wouldn't write anything like that (laughs) you might write 'you were a little bit restless today' but that's it. (Jim N6)*

Three out of the four patients interviewed would have liked more detail in their diary from nurses about what had been going on and how they had reacted. Furthermore, comments in diaries about being 'restless' or 'anxious' with no further explanation were not meaningful to patients.

*...some of what happened was quite scant, there wasn't a lot of detail in it. Em, ah would actually have liked a wee bit more detail, not all the technical stuff, but a bit more detail in it on what went on.*

*...like they said you know ah was 'anxious last night'. What did they do or what was ah doing? How do they express anxiety? (Graham P6)*

Graham attributed the lack of detail to nurses not having enough time, rather than what was described earlier by Jim as trying to write what he thought would be of value to his patients when they were recovering at home. Patients found out from family members' information that was missing from the diary.

*Katrina told me how the physios were massaging ma chest an all that to get the phlegm oot and that's no in there so Katrina's a good diary really! (Alison P4)*

In addition to writing a version of reality another method used by nurses and family members was the use of humour when writing diary entries. This could be in

relation to what was happening inside the ICU with the patient or outside the ICU with the family.

*...you'll maybe get somebody saying "oh ah don't know how to work the washing machine" and you'll say (in the diary) 'oh your man's going about in dirty clothes cause he can't work the washing machine'. You know just something so that they'll have a wee laugh at it later on. (Valerie N3)*

However, nurses only used humour when they felt it was appropriate.

*...ah sometimes try and put a bit of humour (if you can) into it, if it's appropriate. (Carrie N2)*

The boundaries for presenting information in a humorous way appeared to be dependent on the relationship the person writing the entry had with the patient. Therefore, humour used by family members may well be inappropriate for nurses to use when writing to the patient.

*...ah read one once and it said em, it was his son referring to his dad and he says 'dad you'll not be able to get out of this bed because you've got a ball and chain hinging from your you know what!' (laughs). That'll be his catheter bag, so he would read that and probably find that quite funny (Jim N6)*

Patients and family members appreciated finding humour in the diary.

*...some of it can be quite funny when you read it. Although it was serious, but funny as well you know. Some of it's stuck in ma mind. Ah think (laughs) there was one of the patient's daughters was a hairdresser an cut ma hair in the hospital because ah was in there for so long. An one of the nurses put in that ah got ma hair cut to go tae the next ward, you know joking but on a serious side... (John P1)*

Humour was used by nurses to present, in the diary, actual things that happened whilst striking a balance between what was a serious situation to be in however one where normal everyday things occurred.

In summary, presentation of information in the diary came from having an awareness of the patient reading the diary at a later date. Nurses tried to avoid using jargon and structured their entries. Family members and nurses wrote a version of reality in the

diary, to protect the patient from what they believed the patient didn't need to read or what was going to be of no value to the patient. This was determined by the individual writing the entry. However, some patients would have liked more detail in their diary. Humour was often used by nurses and family members to describe events although it was acknowledged by nurses that this might not always be appropriate. When humour was used it helped to balance out the seriousness of the information in the diary.

### 4.3.3 Interpretation of information

Interpretation of information relates to participants views on the information contained in the diary, what this means to them and how they use it. The focus in this section is mainly from the views of patients and family members with the information contained in the diary being written by nurses and family members.

The way that information (contained in the diary) is interpreted can influence the value placed on the diary by an individual and how the diary is subsequently used.

Participants believed that the information contained in the diary was information which would have otherwise been forgotten or lost without the diary, as one patient explains.

*...it's thoughts, an the writing, an that, that you wouldn't have if the diary wasnae there. It would be forgotten thoughts of what's been happening, how they've (the family) felt an that, on a day tae you know daily basis ah think. (John P1)*

The information represented conversations that had taken place, things that had been said to the patient, events involving the patient and what the family were thinking and feeling. Writing this information in the diary, which would have otherwise been forgotten, was regarded by nurses and family members as making memories for the patient from the time that they missed.

*If you're sitting writing it there an then it's a memory. You're making her memories in that diary cause they eight days that she's no here she's no got any memories for them, d'you know what ah mean? An it's a good way of making a memory for her cause she'll be able to tell you*



*exactly what happened that day, when she wasnae even here (laughs)...it's quite impressive when you think about it. (Katrina FM4)*

During periods of observation I often heard the diary being referred to as a memory book. This was mentioned by one of the nurses during interview.

*I think they're seen more as like a memory book for the patient. (Jane N1)*

However, information recorded in the diary and memories made for the patient that were not actually the patients' memories could sometimes be embarrassing or difficult for patients to accept.

*...he'd been in for a long time an had been a bit wild. So his wife had written in the diary like you know 'you pulled your trachy out, an you were trying to get out the bed, an you done this'. An he couldnae believe it with all the things. He found it, he found his quite interesting but ah think he was a bit embarrassed tae you know kinda read what he had been...how he was acting, like his behaviour an stuff. But most of them find it quite interesting, ah think tae read back and see. (Beth N4)*

Patients spoke about being unable to remember what actually happened during the time in ICU. They perceived the information contained in the diary as a way to help them fill in any gaps or blanks they had.

*Ah had no idea what had been going on. Am a complete blank ah would say for what maybe nine days, a complete blank. It (the diary) was filling me in. (Alison P4)*

The idea that information in the diary could help in this way was a view shared by family members and nurses.

*To me the diary is to fill the space that they don't know about. That's what the diary means. Ah don't know if that's what it's for but that's what ah think it's, it's useful for. (Jean FM6)*

*...it's filling in a gap in their life. (Carrie N2)*

Patients using information from the diary to fill in the gaps was frequently referred to by participants in terms of putting together a 'jigsaw' puzzle. In this context,

information contained in the diary was described as either part of the jigsaw, an aid to putting the jigsaw together or both.

*It's just like another part of the jigsaw, I'll no say the picture of the jigsaw but it's, it's helped you put the jigsaw together oh what's happened to you, how your family's been an that. The, the whole picture what's happened to you in that time that you've been in the hospital. It helped me put the jigsaw together. It's not a complete picture but it's, it's an aid to put the picture together...aye it definitely is. (John P1)*

This activity was not restricted to patients recovering at home from critical illness. Family members reported trying to solve their own jigsaw puzzle when visiting their loved one in the ICU, finding the information in the diary useful to remember and make sense of what was going on.

*Every day we came in it was like multitudes of things they were telling us. What they'd done both clinically and medically, from what drugs he was on and all the machines that he was on. It's a lot to take in when you're not in a clinical environment on a day to day basis. Em, so from that point of view looking back you can see and you can piece it all together. It's like a jigsaw. You can piece it together an see why they were doing this an then why they changed it further down the line and why he was coming of this medication or this ventilator or this or this. So from that point of view yes it's good to look back an get, get the clarification in your own mind... (Angela FM1)*

Information in the diary represented progression through the stages of critical illness, the journey towards waking up in the ICU and ongoing recovery.

*More or less from the beginning to the end of what's in it is progression of your getting better. It's just telling you the story of what you've been through when you don't...you've not been there an what's went on while you, you dunno what's happening. So it's just telling you your story up until you more or less, well you wake up after that.*

*It's a progression from when ah was...ah would say seriously ill right up an until ah woke up an knew what was going on round about me. (John P1)*

The progression from being critically ill to getting better and waking up was found by patients when reading their diary. Patients were able to look back and reflect on



what the nurses were doing for them as they progressed through the critical illness experience.

*... ah went through it initially very quickly, just thought 'am reading it'. You know scanning over it and then ah read it a couple of times after it. Ah read it more deeply and ah was, ah was reading what was going on and trends that were appearing. Cause it appeared they seemed to be doing a lot to me and obviously that was when ah was in danger, coming out they were doing less and you know saying they were 'taking this (a line or a tube) out'... (Graham P6)*

When visiting on a daily basis, family members found it difficult to see any improvement or change in their loved one's condition.

*Ah mean some days you were walking in an you would think 'no change in him yet' but when you read the diary the girls (nurses) had put the changes that they had seen on him. So that kinda made you think again, you take another thought and think 'no well he must be improving' you know they wouldnae write that if he wasnae... (Heather FM2)*

Information written in the diary by the nurses detailed changes in the patient's condition based on their observations during a shift or over a number of shifts, as seen in the following diary excerpt.

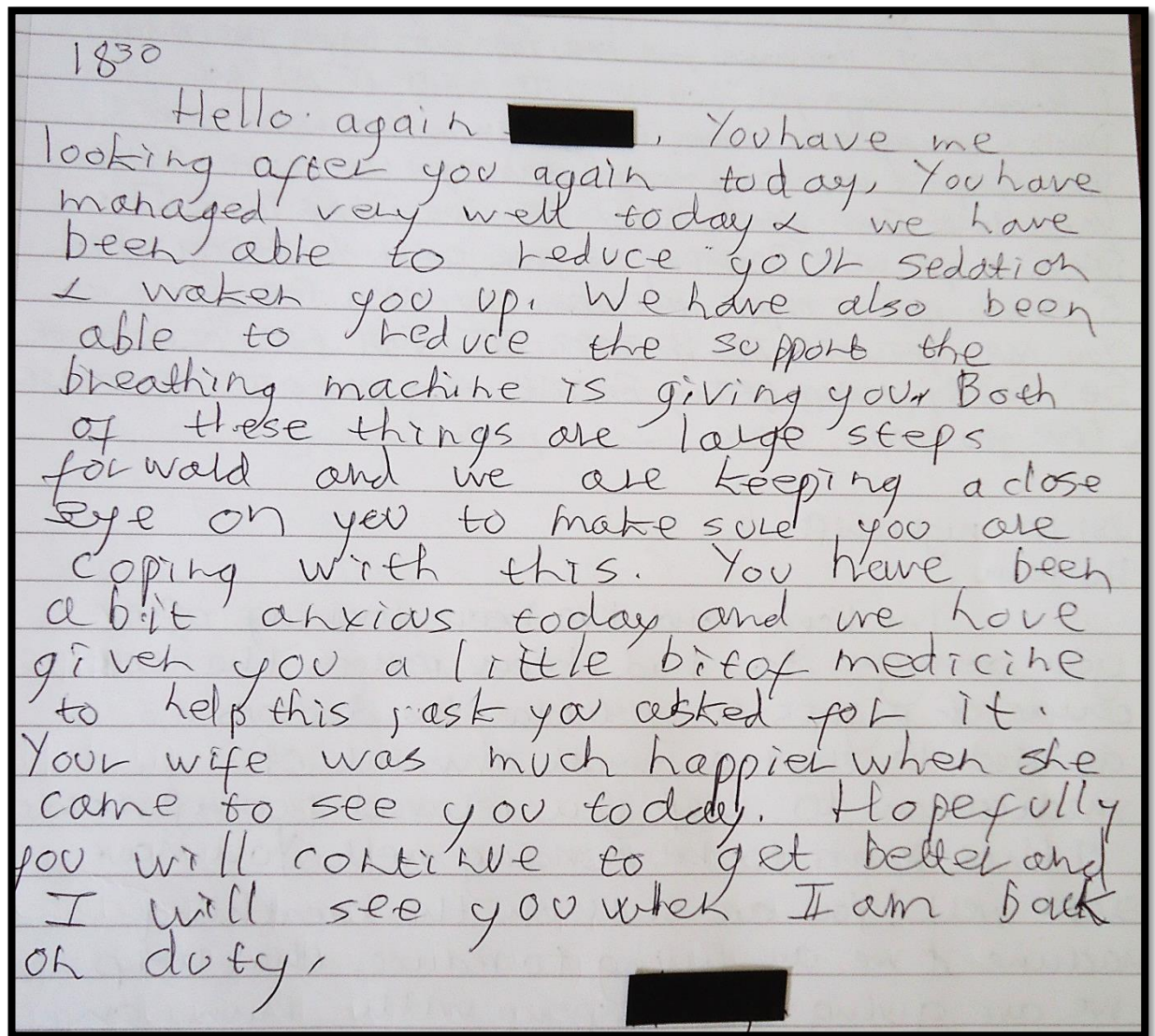


Figure 19: Nurse 'returning to patient' diary entry - P6

Family members trusted the information written by nurses caring for their relative and looked to the diary for evidence of ongoing progress as well as a way to bring things into perspective over a longer period of time.

*It's nice to see where he's been, an where he's going, or where he, where he has reached. (Angela FM1)*

Although family members valued the information written in the diary by nurses whilst they were visiting in the ICU they felt that some of this information might be frightening or scary for their relative to read alone at a later date.

*...realistically ah wouldnae like her tae go through it herself cause a lot of the stuff in it is really quite scary. So it'd be nice if the two of us could sit doon an go through it. (Katrina FM4)*

One patient describes the information he found in his diary.

*...some of the nurses had wrote that 'you've got in tubes' and things an 'your breathing' and 'we had to give you something to your heart' you know so...that's, that's scary stuff to be quite honest with you. (Steven P2)*

Patients had an awareness of how seriously ill they were and what they had been through, learnt from reading their diary.

*It (the diary) gives you an inkling tae just how serious you are...but when you're in there it is, ah would say you are serious when you're in there... (John P1)*

*You see what people have wrote, what you went through, so then you get what you went through yourself. (Steven P2)*

Overall the diary was viewed as something positive, created from a bad situation.

*This is a sort of happy book if you like...relating to something that happened that was quite bad. (Graham P6)*

In summary, the way information in the diary is interpreted can influence the value placed on the diary and how the diary is subsequently used. The information contained in the diary is information that may have otherwise been forgotten without the diary. This information was seen as a way to make memories for patients who had little or no recollection of what had been happening. However, memories were created using the perspectives of family members and nurses, so were not necessarily the patient's own memories.

Patients reported using information in the diary to fill in gaps whilst family members reported using information for their own memory and understanding during the time in ICU. Participants likened this activity to assembling a jigsaw puzzle whereby the diary formed part of the jigsaw and acted as an aid to put the jigsaw together. Information was interpreted as a progression of the patient's journey through their

critical illness. Through reading this information patients and family members were able to reflect on aspects of the experience, ranging from how unwell the patient had been to daily changes in the patient's condition. Family members valued this greatly as often they found it difficult to see any changes or progress being made by the patient however it was acknowledged that such information can be frightening for the patient to read later on. Even so, the diary and the information it contained was viewed positively by patients and their families.

#### **4.3.4 Summary**

The theme information has been presented through the three sub themes: content of information, presentation of information and interpretation of information. An overview of the contents of diaries was given, using photographs of example diary entries and quotes from participants. There was found to be a difference in the content of nurse diary entries compared to family member diary entries. In addition to this, diary entries from those not able to visit the ICU were identified, for example drawings from young children. Whereas patients were unable to write in the diary, however entries were written by some patients after the ICU stay. Diaries were updated on a regular basis by nurses and family members, providing the patient with a record of what happened when they were in ICU, including 'day to day' information and information about what family members were going through. Family members reported reading information in the diary while visiting in ICU and although this reflected verbal updates given by nursing staff, on occasion unexpected information was found.

Nurses and family members decided what to write in the diary, knowing that the patient would eventually read this. Structuring diary entries, avoiding the use of jargon and writing a version of reality to protect the patient were approaches taken by nurses and family members to write or present information in the diary. However, some patients would have liked more detail in their diary. Another approach often used by family members and nurses was the use of humour, in describing events, to try and balance out the seriousness of the situation and therefore information written in the diary.

Participants acknowledged that without the diary, information relating to the ICU stay and what was happening at that time would be forgotten. Therefore, the diary was a way of making memories for patients, memories created from the perspectives of nurses and family members. Reading information in the diary helped patients and family members with their understanding and allowed them to reflect on different aspects of the critical illness experience. Interpreting information as a progression of the patient's journey allowed family members to see changes in their loved one. However, there was concern that patients might be frightened by what had been written, yet despite this concern diaries and the information written were viewed positively.

#### 4.4 Communication

Diaries are used as a way for nurses and family members to communicate with the patient, providing the patient with information about what happened when they were in the ICU from the perspectives of nurses and family members who are present during this time. However, it became apparent from the findings in this study that the role the diary played in communication and the way it was used by participants to communicate extended beyond the basic provision of information for patients after ICU to help them with their recovery. The diary was often used by nurses, family members and patients as an aid to communication during and after the time in ICU. For example, during the time in ICU the diary gave family members a way to communicate with their loved one when they visited.

The theme communication reveals the various ways in which the diary is used for communication between nurses, family members and patients during and after ICU. Three sub themes were identified in the theme communication: *presence*; *facilitating communication with the diary (during and after the time in ICU)* and *communication through the diary*. Presence relates to patients, families and nurses being there in the ICU and the role of the diary in giving presence to those individuals in this setting. Facilitating communication with the diary gives insight into how nurses, family members and patients use the diary to facilitate communication during and after the time in ICU. Communication through the diary

is concerned with more subtle or unintentional communication occurring from the diary being present.

#### 4.4.1 Presence

Presence relates to patients, families and nurses being there in the ICU and the role of the diary in giving presence to those individuals in this setting. The sub theme presence arose initially from participants talking about themselves or others as either being ‘there’ or ‘not there’. Patients spoke about themselves as not being there in the ICU and family members spoke about patients or their loved one as not being there. Not being there and being there was dependent on the patient’s level of consciousness at any given time. Family members who visited were there with their loved one physically and mentally yet they too spoke about themselves as not being there as they (the family) were not able to be there all the time whereas the nurses were. Therefore, the following terms ‘there’ and ‘not there’ will be used to frame the findings from the sub theme presence.

Patient participants required a period of sedation and ventilation to support them through their critical illness. Although patients were physically there in the ICU, their altered level of consciousness meant that they were perceived as not being there by the patients themselves and their family members. Family members expressed patients not being there by using the term ‘out of it’ to describe their loved one when they were sedated, as explained by one family member.

*Pete was completely out it for at least two weeks because they had just put him to sleep so’s he wouldn’t move around because his stomach was lying open and you know one thing an another... (Mary FM5)*

Patients referred to themselves as ‘not there’ and had little or no recollection of what happened to them during the time in ICU.

*When you’re not there all this is happening round about you an you have nothing to... How do ah put it? Ah was gonna say go on. (John P1)*

The experience of visiting someone in ICU who was ‘out of it’ or ‘not there’ was challenging for family members and they used the diary, as one family member explains.

*You're limited to what you can say tae somebody that's no even really...she was sedated, she wasn't with it know what ah mean. So it was something for people tae dae just tae even pass that wee five minutes an just to let her know that we had been there. (Lynn FM3)*

The diary gave family members something to do during visiting time, something to focus on. They were able to let their loved one know that they had been there in the ICU with them. However, once the patient was more awake or 'there' the diary was used less frequently by family members.

*...the days she was like that (awake) we didnae tend tae write very much, ah would maybe write a paragraph an say 'well you're awake just now so am telling you all, more tomorrow' type thing. Em, an because she was awake we kinda drifted away fae the diary because we were talking tae her. (Katrina FM4)*

Family members eventually stopped using the diary when the patient was fully conscious, able to remember things and could hold a conversation.

*Ah mean he just gradually got better and better an then when he got sent intae the, the actual ward we just stopped the diary then because by that time he was remembering things and he was talking to you quite freely then. (Mary FM5)*

Patients viewed the diary as a record of the time when they were not there or unable to understand what was going on, explained by one patient.

*It was more or less, it's a record of when you weren't there you know...*

*It's telling you what was happening day to day when you weren't there or couldnae understand... (John P1)*

The diary contained information about the patient, what was happening when they were not there and gave a record of who had visited or phoned (see 4.3.1 *Content of Information*). Furthermore, the diary gave presence to the patient in ICU and those who visited or enquired about them, extending to family members who were unable to visit, such as children.

*We just kept saying (in the diary) that all the grandkids an all that, she's got thirteen grandkids you know, em just that all the grandkids were asking for her... (Lynn FM3)*



The act of writing in the diary situated family members, friends, nurses and other healthcare professionals with the patient in ICU. Furthermore, writing to the patient directly on a regular basis maintained the patient's own presence in ICU.

Family members looked to the diary to find out what had been going on with their loved one when they were unable to be with them or 'not there'. For example, night shift was identified as a time when family members were not there with the patient and entries written by the nurses on night shift were read by family members the following day to find out what had been happening with their loved one during this time.

*When we looked at Jean's (diary) it gave you an insight actually what, what was going on at night when we weren't there and the same with this one (diary) (Graham P6)*

Some family members struggled with only being allowed into visit at certain times and as a result felt that a lot of the time they were 'not there' with their loved one and missed out on things that had been happening, as one family member explains.

*We don't know when she woke up, or when she went back to sleep, or what she ate that day, or if she even ate that day, or was she conscious that day. D'you know what ah mean we don't know cause it's two hours out of twenty four. It's no a lot when you think about it. (Katrina FM4)*

For this family member (Katrina) in particular, the information that the nurses wrote down meant a lot as Katrina was unable to tell her mum everything that had been happening because she was not always there with her mum, whereas the nurses were.

*The nurses are in there with her all the time an the fact that they were writing in it (the diary). It did it really touched me cause we cannae tell her these things because we're no allowed in there... (Katrina FM4)*

When family members did get into visit they were faced with the reality that their loved one may not know they had ever been there, as described by one family member.

*You know he's been sleeping for three weeks. You know he doesn't know what, what's happened. He doesn't know anything at all. Who was here, he doesn't know if ah was here... (Jean FM6)*



This reality was discussed by the patient participants who had little insight into who had been with them during this time.

*Ah don't know half the people that was visiting me  
sometimes...sometimes ah didn't know who was there. (Steven P2)*

Nurses recognised that the patient may not remember their family had been there in the ICU with them and encouraged family members to write in the diary, one nurse gave an account of what he told family members.

*...just write messages for your relative that they would like to read when they improve and when they get better, it's nice to know that you've been here you know they don't know you've been here. You know the illness can go on for over a week then you know you'll have a written record of being here that will comfort the person...after they've recovered. (Jim N6)*

Nurses identified the presence of family members in ICU as a key issue and ensured presence of family members was prominent in the diary by directing family members to write about their own presence in the ICU, when their loved one was 'out of it' and unable to know or remember.

Patients were able to get to know who had been there in the ICU from reading the diary and from this realised they were not alone.

*...ah maybe didn't even remember them being there but because they'd written it am like that "oh aye you were in". (Alison P4)*

*You read through it and you get, it lets you know that they were coming in...different things ah went through before ah woke up they went through it with me, not physically but they went mentally through it. (John P1)*

It was important for families to know that their loved one was not alone. One family member introduced the presence of an 'angel' with their loved one which they wrote about in the diary.

*Ah used to say to her "av left ma angel with you, I'll pick him up when you're ready for me to get him back" an ah put that in the diary quite a lot. (Lynn FM3)*

Nurses reported using the diary to let patients know that they were not alone and someone was always there with them, as one nurse explains.

*...quite often I'll say you know 'we're all here' you know 'the nurse is with you all the time and your family have been in'. Em av even been known to say, like one night ah wrote in somebody's 'you were a bit upset so I sat with you and held your hand till you fell asleep' you know things like that, just anything really. (Valerie N3)*

Presence of the family was therefore not just narrated by family members in the diary but by nurses as well, in addition to the nurses writing about their own presence with the patient. Although nurses wrote directly to the patient, family members were reassured from reading such entries that someone was there caring for their loved one when they were not there.

*...you've got them writing to Graham and telling him all this stuff and when you read it, it just makes you feel so confident that they're, you know that they're taking care of him. You know that there's...someone there. (Jean FM6)*

In summary, the patient's ability to assert their own presence in the ICU was compromised as a result of their critical illness and the supportive treatment they required during this time. Both patients and their family members spoke about not being there. The diary gave family members an opportunity to record their own and other peoples' presence in the ICU whilst acknowledging that their loved one was there even when they were considered not to be. Family members wrote in the diary until the patient began to waken up, at which point the frequency of diary writing decreased. The information in the diary therefore represented the time that the patient was not there or unable to understand what was going on and thus acknowledged that the patient was present during this time. Furthermore, the diary gave presence to those who had been at the patient's bedside or enquired after the patient.

Family members had limited access to their loved one when they were in ICU which left them feeling like they (the family) were not there with them. However, nurses were there all the time and wrote about being there with the patient, documenting nursing presence as well as what was happening to the patient. Family members

appreciated nurses writing in the diary to their loved one when they (the family) were not there. Furthermore, when family members visited it was recognised that their loved one may not remember this so nursing staff encouraged family members to write in the diary to ensure the patients knew their family had been there. Patients were able to read about who had been there during this time. Nurses and family members used the diary to reassure patients they were not alone, someone had been there with them. One family member even reported leaving an angel to watch over her loved one and wrote this in the diary, therefore giving presence to a supernatural being in the ICU. Family members benefitted indirectly from reading nursing entries as what had been written reassured them their loved one was being looked after when they (the family) could not be there.

#### **4.4.2 Facilitating communication with the diary**

The diary is used to facilitate communication between nurses, family members and patients during and after the time in ICU. As discussed in the previous sub theme the diary can give presence to patients, family members and nurses in the ICU. Once a person's or group's presence is established, the diary can be used as an aid to facilitate communication with that person or group. During the time in ICU family members and nurses used the diary in various ways to facilitate communication with each other and the patient whereas after the time in ICU the diary was mainly used by patients. Therefore, the sub theme *Facilitating communication with the diary* has been separated into two sections: *Communication during the time in ICU* and *Communication after the time in ICU* to reflect the way the diary is used and the role it plays at these different times.

##### **Communication during the time in ICU**

The diary was used by nurses and family members to facilitate communication with the patient and each other during the time in ICU. The diary opened up a channel for communication to take place and facilitated communication interactions between family members, nurses and patients. The following section will demonstrate the number of ways in which the diary was used by participants to facilitate communication during the time in ICU.

Family members used the diary to facilitate communication with their loved one in the ICU. The diary gave family members a way to communicate with their loved one, as explained by one family member.

*Having the diary and writing the diary helps me communicate to Graham when ah can't. You know it just opens up that, as if he was there, as if ah could talk to him. (Jean FM6)*

The diary gave presence to Jean's husband Graham and opened up a channel through which she could connect and communicate (talk) with him, when he was not there. Participants often referred to the diary as a communication 'aid' or 'mechanism', a tool to facilitate communication.

*If she was still sleeping I'd lift the diary an I'd talk to her that way because she was sleeping, so ah used it more as a kinda communicating mechanism if you like because, because she cannae answer me it was a way of me letting her know.*

*Ah got to communicate with ma mum when she was sleeping. (Katrina FM4)*

Family members used the diary to communicate or talk with their loved one by writing in the diary when their loved one was unable to respond. A one-way conversation between the family member and the patient occurred. Family members valued having the opportunity to communicate in this way when everyday methods of communication were not possible, for example talking to someone on the phone or in person (a two-way conversation).

*Family members often spoke about using the diary to communicate directly with their loved one in the moment, in the ICU. Although they were invited by the nurses to write in the diary for their loved one to read in the future, the diary for family members was used to communicate in the present. ('Reflections on family members and the theme communication' CM fieldnotes)*

Nurses recognised how difficult it could be for family members in this situation and the important role the diary played in facilitating communication with patients in ICU. One nurse discusses this in the following example.

*Ah know that her daughter was finding it really hard because she spoke to her mum every single day, like three times a day and things. So she was finding the fact that her mum was in there and she couldn't speak to her really hard. So ah think that her daughter liked the fact that she had a diary and that she could write down, it was as if she was having conversations with her mum. (Beth N4)*

Not knowing what the patient could hear or remember in the ICU was an issue raised by family members and nurses who used the diary to record information for patients which could be forgotten or lost (see 4.3.3 *Interpretation of Information*), as one family member explains.

*Ah thought it meant a lot because obviously Steven, well ah, ah, ah would think Steven was totally sedated. He wouldn't have been able to hear, might have been able to hear but the wee nurse says she was unsure whether he could hear. An ah thought 'well its good you kin put your thoughts on the diary then an he kin go back an read it.' (Heather FM2)*

Therefore, family members appreciated having the diary to record information they wanted to share with their loved one in ICU that could be read at a later date.

The support family members received from using the diary to communicate with their loved ones extended to family members who were unable to visit in the ICU. For example, nurses encouraged family members to get children to write letters and draw pictures which were then placed in the diary for safe keeping (see 4.3.2 *Presentation of Information*).

*The fact that they don't let kids in but she can still communicate with her gran ah thought was fabulous, because if she'd done all that (written letters and drawings) they'd ah sat it up on the windae sill usually an it woulda got binned eventually, but it's something mum can keep. (Katrina FM4)*

Encouraging family members to use the diary in this way meant a lot to family members who were able to visit and gave family members who were unable to visit an opportunity to continue to communicate with their loved one, as seen in the following diary excerpt from a child.





Figure 20: Family member 'child's get well card' diary entry - P4

Additionally, family members used information written in the diary by nurses to facilitate communication interactions with nursing staff in the ICU. Nurses routinely signed their name at the end of each entry written to the patient and this was noted by the patient's family members. Over a period of time family members got to know the names of individual nurses who had looked after their loved one.

*...you know they write it down at the bottom and they would write 'Mary' or whatever. So then am able to...when they came over to me and the nurse would say "Hi you know I'm Mary" an ah would go "Oh Mary". You know and it's as if ah know her...you know and then it's easier to speak. (Jean FM6)*

Diaries can give presence to people in the ICU (see 4.4.1 *Presence*). As seen in the above example family members found it easier to communicate with nurses who were present in the diary as they already knew the nurse's name, even if they had never met that nurse on duty before. Likewise, although nurses did not routinely read the diary they reported using information in the diary to facilitate communication with family members. For example, when nurses were struggling to communicate with a family or wanted to find out how the family were and what their understanding of the situation was they would read what had been written in the diary, as one nurse explains.

*If the family aren't really communicating well with you, you can have a wee look in the diary to try and get a handle on what their take is sometimes. So you can judge some of the questions you wanna ask an, an maybe try an get them to open up a bit more cause sometimes people can do it a bit better in a diary then they can to us. (Jim N6)*

The diary enhanced communication with the family by helping nurses to initiate and guide conversations as well as providing a forum for the family to open up. Furthermore, nurses were able to use the diary to explain procedures and give information to patients and families about what had been happening (see 4.3.1 *Content of Information*). However, despite recognising the potential that the diary had to facilitate and enhance communication in the ICU and the role it could play in providing information to patients and family members, one nurse expressed strong views about using the diary to communicate.

*Ah think you have to speak to them. Ah think, ah love, ah think the diaries are great and ah think they're important but ah don't think we can rely on them to communicate with visitors. Ah think the best form of communication is talking, is chatting, is you know even with the families its general chit chat, "what have you been doing today?"*

*Ah don't think that if we didn't have the diary we wouldn't have that ability to do it (communicate). You could use it as a (way of) leading into something else if you wanted to. (Fiona N5)*

Therefore, although the diary can be used by nurses as a tool to facilitate communication and provide information to families and patients about their stay in ICU it is not necessarily the only way or best way to communicate in this setting. Nurses have the ability to communicate without a diary and should not forget the value of communicating directly with family members and patients at the bedside.

In addition to using the diary to facilitate communication with family members, nurses were able to use information written by family members to facilitate communication with their patients in ICU. For example, nurses reported looking to the diary for information when a patient was starting to waken from the sedation they had been given. The information written by family members was used by nurses to calm, reassure and re-orientate patients to their surroundings, as one nurse explains.

*You know you can kinda say tae them "oh your daughter will be up, or your grand..." You know and you kinda know names and things. It is, ah find it does kinda help people to get a bit less confused and maybe a bit less frightened when they're starting tae wake up. Em, ah find it quite useful for that...if the relatives have wrote in it. (Beth N4)*

However, as noted the extent to which nurses could use the diary in this way was dependent on whether family members had written in the diary or not. Additionally, information written by family members was used by nurses to generate topics for conversation when the family were in visiting, as explained by one nurse who discovered through the diary that her patient liked to sing.

*That kinda gave me a wee kinda conversation with the family as well cause ah was like "Oh does she like to sing? What does she like to sing?" (Carrie N2)*



Therefore, nurses used the diary in ICU as a way to communicate with patients about what was happening as well as facilitating communication interactions with family members and patients during this time.

Patients reported being encouraged by family members and nursing staff to write in the diary when they were awake in the ICU however mixed experiences were reported by patients, as demonstrated in the following two examples. One patient described how his wife encouraged him to write in the diary when he was unable to speak.

*Jean tried to get me to write something in. Ah couldn't write cause that's the time ah couldn't speak and she says "well try and write something down" but ah was, ah just couldn't do it. Ah thought it was alright but Jean was saying "no I can't understand" so that was quite infuriating. (Graham P6)*

The experience of trying to write in the diary was frustrating for the patient (Graham) and his wife (Jean) as Graham was unable to write anything that Jean could understand. Another patient (Steven) was encouraged by his nurse in ICU to write in the diary.

*One of the nurses gave, said tae me day six or whatever it was "that's your diary there if you want to start putting anything in it, it's up to you" (Steven P2)*

The experience for Steven and his wife (Heather) was quite different from the previous example. Steven was able to write and used the diary as a way to communicate with or acknowledge people who had visited him and written in his diary when he was critically ill, his wife Heather explains.

*Ah think more or less thanking everybody an different things like that, aye he put in an had that he 'didn't know much about the days' an that 'the monsters were going away'. (Heather FM2)*

However, as demonstrated in the examples patients using the diary in ICU as a way to communicate was dependent on the patient wanting to and being able to write in the diary and then family members or nurses being able to understand what had been written if the entries were directed at them.

Nevertheless, the idea that a patient might be able to contribute to and communicate using their own diary was viewed positively by family members.

*...eventually I'd like to think that he would be writing something in it, or telling somebody what to write, to put in it. So that's gonna be another good sign. (Angela FM1)*

*When ah seen Steven was writing in it, ah mean that was good that he'd put his own wee bit in it... (Heather FM2)*

In Summary, the diary was used by nurses and family members to facilitate communication with the patient and each other during the time in ICU. The diary opened up a channel for communication to take place thus facilitating communication interactions between family members, nurses and patients. Family members used the diary as a way of communicating with their loved one in the ICU when there was no other way. Writing in the diary was experienced by family members as if they were talking and having a conversation with their loved one. Additionally, the diary enabled family members to record and share information at a later date with their loved one that might not have been heard or remembered. Therefore, the diary supported family members in communicating with their loved one during the time in ICU.

Information recorded in the diary was used by nurses and family members to facilitate communication with each other. Family members got to know the names of nurses who were present in the diary, assisting communication with nurses when they were on duty. Likewise, nurses were able to initiate and guide conversations with family members and patients from information written in the diary. However, this was dependent on family members writing in the diary. One nurse cautioned against relying on the diary to communicate, recognising the value of communicating directly with family members and patients at the bedside. Nurses wrote to the patient and often encouraged patients to write in their own diaries when they were able. Patients had mixed experiences using the diary to communicate in the ICU which appeared to be in relation to their ability to write and make sense. The diary opened up a channel for communication to take place, acted as an aid to communication

interactions between nurses, family members and patients and was used to record and access information.

### **Communication after the time in ICU**

The diary was used by patients to facilitate communication after the time in ICU. Patients used the diary as an aid to communication and as a way to communicate with others about what happened to them when they were in ICU, as one patient explains.

*It fills in those gaps. You know if somebody asks me you know “what happened?” then ah can say, ah can refer back to this. Ah have said a few times “have a read at that, you’ll see roughly...” and talk, talk them through it. (Graham P6)*

Patients shared their diaries with family and close friends who visited at home or in hospital, after ICU. The diary was used to talk through events, as one patient explains.

*Well we’d went through it (the diary) but we did, we spoke about it, everything in it, well most things in it. (Alison P4)*

Reading through the diary together initiated and opened up conversation between patients and their family members. Going back through the diary allowed patients and family members to talk about their experiences and memories from the time in ICU. One patient, who had previously been a family member in ICU, explains.

*Yeah we’d go through it (Jean’s diary) together, we’ve read it quite a lot, quite a lot cause Jean has no issues about going back, cause when she remembers, Jean remembers her being in ‘Jeanie land’. That’s what we called it yeah so we just, we just had a good laugh about that (Graham P6)*

However, using the diary to communicate with family members about what happened was dependent on whether the patient wanted their diary, had access to their diary and whether they felt ready and able to read their diary at that time.

*Ah said to him “do you want to read it?” and he said “no” but ah knew that, ah knew he would say no, so it’s on the bookshelf next to mine! (Jean FM6)*

*Av been told by Emma (lead diary nurse) of some of the experiences and how patients have em felt about having the diary. Some people haven't read the diary for a long time, until maybe a year until they feel ready to read it. (Jim N6)*

Family members viewed the diary as something they could use in the future, as a family, to discuss and reflect on what happened when their loved one was critically ill. The appeal of using the diary as an aid to communication after ICU was often referred to by family members when others in the family had been unable to visit in the ICU or did not fully understand what was going on at that time. A family member explains.

*Our wee grandson who's 2 d'you know maybe if it was possible say 10 or 12 years down the line for him to read that an see, ah don't know if he would really remember back this far but he, he knows that this man's been in his life, his whole life an then to suddenly not be there an then suddenly come back again.*

*Maybe further down the line for somebody like him tae read it an obviously Sarah being the younger one an maybe in 5 years time she'll understand something different then what she does just now. (Angela FM1)*

In summary, patients used the diary as an aid to communication and as a way to communicate with others about what happened when they were in ICU. Patients shared the diary with family members to facilitate communication about events occurring in the ICU. Experiences and memories were discussed when reading through the diary together, therefore the diary helped to initiate and open up conversation between patients and their family members. Re-visiting the diary several times with a family member was not uncommon. However using the diary to facilitate communication about what happened was dependent on the patient wanting their diary and feeling ready to read through it with a family member. Family members identified the diary as a potential resource that could be used in the future to discuss what happened with others, for example children who at the time did not know or understand what was going on when their loved one was critically ill in ICU.

### 4.4.3 Communicating through the diary

The previous section focused on how the diary was used by nurses, family members and patients to facilitate communication during and after the time in ICU. The sub theme *communicating through the diary* tries to unpick some of the more subtle or unintentional communication occurring as a result of the diary being present. Two areas were identified, *the unspoken word* and *communication in relationships*. It became apparent from interviews that family members were communicating through the diary things that they would not normally say to their loved one, coded as ‘the unspoken word’. Communication in relationships occurred when an entry or entries written in the diary informed or prompted communication between two or more people, usually involving the person who wrote the entry.

#### The unspoken word

The unspoken word is concerned with people writing things in the diary that they would not normally say out loud to one another. Family members were using the diary as a channel through which they could communicate ‘the unspoken word’. Having the diary to write in was likened by one family member to sending a text or a letter to someone, something that could be kept.

*...sometimes when you write things down ah, ah feel it's nice tae have it. You know ah like texts as well d'you know because you can sometimes, you can say something in a text or a letter that you wouldn't necessarily verbally put out there... (Angela FM1)*

One reason identified by family members for not being able to say something to someone verbally, other than the issue of presence in the ICU (see 4.4.1 *Presence*), was the emotion attached to what the family member wanted to say, as described in the following quote from a family member who had previously been a patient in ICU.

*...even in ma diary, there's things in ma diary nobody would ever to my face say, it's too painful. Things like that are too painful for people to say but they can write them down for you. (Jean FM6)*

The ‘painful’ things that family members did not feel able to say but were able to write down in the diary were related to the experience of having a loved one in ICU. Family members were faced with the possibility that their loved one may not survive.

*...you don't know what somebody means to you until you're ready tae lose them. (Katrina FM4)*

Nurses recognised how difficult it was for families in ICU and observed family members using the diary to write down how they felt about their loved one, as one nurse explains.

*It's quite em hard going and stressful and ah think it's good sometimes that they (the family) can write down all their frustrations and stresses or just write down how much they're missing them (the patient) and they don't have to say it. It's maybe easier...to write it down than it is to say it to the person. (Beth N4)*

Family members experienced emotional support through writing in the diary, which will be discussed further in the next major theme Emotion (see 4.5.2 *Emotional support*). Writing ‘it’ down rather than saying ‘it’ to the person was witnessed by others present in the ICU, as seen in the following quotes.

*Ma youngest sister...was very close to Graham you know it was like a big brother to her and em she was very upset. So she's writing things like 'don't you dare die' you know and things like very heartfelt em things that she wouldn't say. (Jean FM6)*

*...sometimes they (the family) find it difficult communicating that but they can write it down in a diary, that's what av found. (Jim N6)*

Nurses were fully aware that family members wrote things in the diary to their loved one that would not necessarily be said and respected this, as one nurse explains.

*...sometimes people pour their heart out in the diary...there's things they maybe wouldn't say. Em an it's quite a kinda confidential thing for us to read sometimes, some things that people put in. (Beth N4)*

One family member witnessed her brothers writing things in the diary that were out of character, demonstrated in the diary entry on the following page.



hey mum its your big ASS\*\*\*\* of a son here  
 Buckle down to see you and as per you are  
 the Best looking MOTHER in here and we miss  
 you so so much our wee Chats on phone about  
 the biggest lot of rubbish we always talk about  
 lol we been coming to see you on both visits  
 this well just to make sure you still like ha  
 you have great nurses looking after you so im happy  
 with that and can settle abit better.

Been thinking of you all day cos on just sat  
 about nurse hiles a test cause took +  
 a walk to get some fresh air to clear my head  
 but did that work not a chance lol so all i have  
 done is sit and make buttons to see you.  
 trying to tell you think you might be proud  
 go picked up by a Supplement Company to represent  
 them so so when that goes and once you  
 fit and out this place me & my beautiful mum  
 will be going to that gym to keep you fit and  
 healthy and keep you off dem fags eh? lol  
 m. is dying to come in and see you shes asking  
 about you non stop <sup>so</sup> she will be in this week  
 to see you and kids asking for you too so the  
 love is defo flowing for you for sure as it always  
 is. Just before i go i like to keep you cool  
 and dab you chug a bit of personal care for you  
 mother you like my big Baby lol 😊

Love you so much mums your big Boy

Figure 21: Family member 'unspoken word' diary entry - P4

*Ma brothers are not emotional, even slightly. Ma younger brother...he's done 'love you loads your big boy Chris'. Chris doesn't talk like that because he's a big body builder an he's hard as nails an doesnae talk like that. An he's wrote 'your big boy Chris' or something. An you just think that's something she's (mum's) got forever cause he'll never say that to her ever an she's got that there you know, how he feels about her an ah think that's fabulous... (Katrina FM4)*

In contrast, the patient whom the diary entry was written for explains how she felt about the entries her son(s) had written.

*Ah suppose ah could use it (the diary) to blackmail ma sons that don't phone me or come and see me. Ah could use it for that right enough, all these empty promises in here (the diary). You know, it's alright when they think their mother's dying 'oh mum' but when she's alright 'get on with it'...boys. (Alison P4)*

Therefore, reading unspoken words in a diary was not necessarily appreciated by the person it had been written for if that person did not believe or experience what had been written. Despite this, all the patients interviewed including the previous patient (Alison) appreciated close family members and friends writing in their diaries, as one patient explains.

*...they've been through the, the mill too. An they're just giving you thoughts how bad they feel about it and how hard it is for them.*

*...ah think even reading the diary an seeing what she ('the wife') was putting in, it's brought us closer together, definitely. But we are a close family as it is...more so now, because of what's happened tae me. (John P1)*

Reading the diary gave patients insight into what their family had been through, bringing the patient and their family closer together. Family members and patients were able to share the experience of critical illness, from different perspectives, through writing and reading diary entries containing the unspoken word.

In summary, the unspoken word shows family members communicating through the diary in writing things that they would not normally share or say out loud to their loved one. The diary created a channel for the unspoken word to be communicated and once written down this was something that could be kept. When it was too



difficult or ‘painful’ to communicate verbally family members found that they could write it down in the diary.

Nurses recognised how difficult it was for families in ICU and alongside other family members witnessed the diary being used to write ‘it’ down. Patients appreciated what close family members and friends had written however there was an example where one patient was unhappy with what family members wrote in her diary. The unspoken word, written by family members during the time in ICU, is related to the reality and experience of having a loved one in ICU who is critically ill and may not survive.

### **Communication in relationships**

Communication in relationships occurs when an entry or entries written in the diary lead to communication in a relationship between two or more people, usually involving the person who wrote the original entry. A variety of relationships exist inside and outside the ICU when the patient is critically ill and although the evidence is limited there were some examples of the diary potentially enhancing communication in existing or newly formed relationships between family members, nurses and patients.

During the time in ICU the diary was kept at the patient’s bedside for nurses, family members and friends to use. The diary was written to the patient and the information it contained was accessible to those who were allowed at the patient’s bedside. For example, when family members visited they could read what other family members or nurses had written, sometimes acting as a catalyst for further communication to take place, as demonstrated in the following example between two family members.

*...the bit in the diary that ah put aboot being lonely. Ma brother did, he picked up on that and he phoned me that night actually. He says “you were in here at three tae four the day an you’ve wrote in that diary that you’re lonely”. Ah says “aye” an he says “want me tae bring the wee man up a wee while an we’ll get a blether?” He brought his son up tae ma house an the three kids were upstairs playing an he sat doon an he was blethering tae me...ah felt like that made a difference...*

*...I’d say it’s changed mine and ma older brother’s relationship because he’ll say, even tae this day he’ll say tae me “if you need help Katrina you*

*need to let me know". He knows now that am no as strong as he thinks ah am so it's kinda helped a bit with ma brother. But like ah say ah don't even know if ma other brothers read it. (Katrina FM4)*

However, being able to identify and act on what one person wrote in the diary was dependent on others reading the diary and being willing to discuss what had been written. Some family members viewed writing in the diary as a very private activity and did not discuss with others in the family what they were writing or what others had written during the time in ICU, as one family member explains.

*...nobody discusses what they're writing even though everybody knows everybody can read it. It's something you don't, I found it's something we don't discuss.*

*...you just don't, it's kinda like well that's your private wee bit. You can put in whatever you want an ah know they can read mine, an ah know they've went back and read you know other things but em no...no didn't discuss it no. (Jean FM6)*

Another family member spoke about the diary 'opening up conversation' in her family.

*Ah think it's (the diary) opening up the conversation d'you know. Em...it's making you deal with things that you...well nobody can comprehend what, what anybody's going through in a situation like this. Ah think it's...eh the situation's brought the family a lot closer, we're talking a lot more about how we're all feeling. Whereas you tend to go through your day an like "oh ah had a good day the day" or "ah had a bad day" an just general...without all this having gone on. Whereas now ah think, you're more conscious of other people's feelings and what kinda day they've had or how they're getting through it. (Angela FM1)*

However, referring to the diary and the experience of having a loved one in ICU simultaneously, makes it difficult to determine if it was the diary that enhanced communication between family members, the experience of having a loved one in ICU or a combination of both.

Nurses did not rely on the diary to communicate with their patients and family members therefore communication occurring in relationships between the nurse and the patient or their family appeared to happen without the presence of the diary.

However, some nurses believed that the diary enhanced communication in the relationship they had with the family, as one nurse explains.

*I think it (the diary) enhances it (communication) a bit ah think. Ah think it opens things out a little bit and if...an if relatives read what nurses have written then it's, then it seems quite personal then you know they understand that you know...well maybe we're here for their relative's best interest as well and we're only human and we're just communicating on that level with them (Jim N6)*

In summary, communication in relationships describes examples of situations where diary entries lead to communication between two or more people. Family members read what each other had written and sometimes an entry would be discussed further. However other family members did not discuss anything they wrote in the diary with each other as this was private to them. Within families the diary helped them deal with the situation, opening up conversation and having an awareness of what others in the family were thinking and feeling. Nurses recognised the potential the diary had in enhancing communication between themselves and family members through demonstrating their role as an advocate for the patient.

#### **4.4.4 Summary**

The theme communication illustrates different ways in which the diary is used for communication. The diary establishes presence of patients, family members and nurses in the ICU, playing an important role for individuals involved directly and indirectly in the patient's experience of critical illness. Information written in the diary represents time in which the patient was not there, thus acknowledging the patient's presence. As patients began to waken up and communicate, family members wrote less in the diary, further supporting the idea that the diary represented and gave presence to the patient in ICU. Nursing presence documented in the diary was appreciated by family members and patients as it reassured them that the patient had not been left on their own. This was particularly important for family members visiting the patient in ICU as they could not be with their loved one all the time. Furthermore, patients read about who had been there when they were critically ill.

The diary helped to facilitate communication between family members, nurses and patients by providing a channel for communication to take place. Whilst in ICU family members used the diary to communicate with their loved one when there was no other way, experienced as talking or having a conversation. Additionally, the diary contained information that helped to facilitate communication between nurses and family members. However, this was dependent on family members writing in the diary. Furthermore, when patients communicated with others after ICU about what happened they referred to their diary, for example to discuss memories and experiences with family members. However, patients had to be at a stage where they had read their diary and wanted to discuss this. Therefore, the diary helped to initiate and guide conversations in the ICU and after ICU when people interacted with the diary.

Finally, communicating through the diary was reported, which involved more subtle or unintentional communication occurring because of the diary being present and the experience of having a loved one in ICU. This took the form of the unspoken word and communication in relationships. The unspoken word was written by family members, when they were unable to say this out loud but could write it in the diary. For example, feelings that would not normally be shared. Whereas communication in relationships occurs from reading and discussing information written in the diary by others. This type of communication can be supportive to family members in the ICU and enhance interactions between nurses and family members.

## 4.5 Emotion

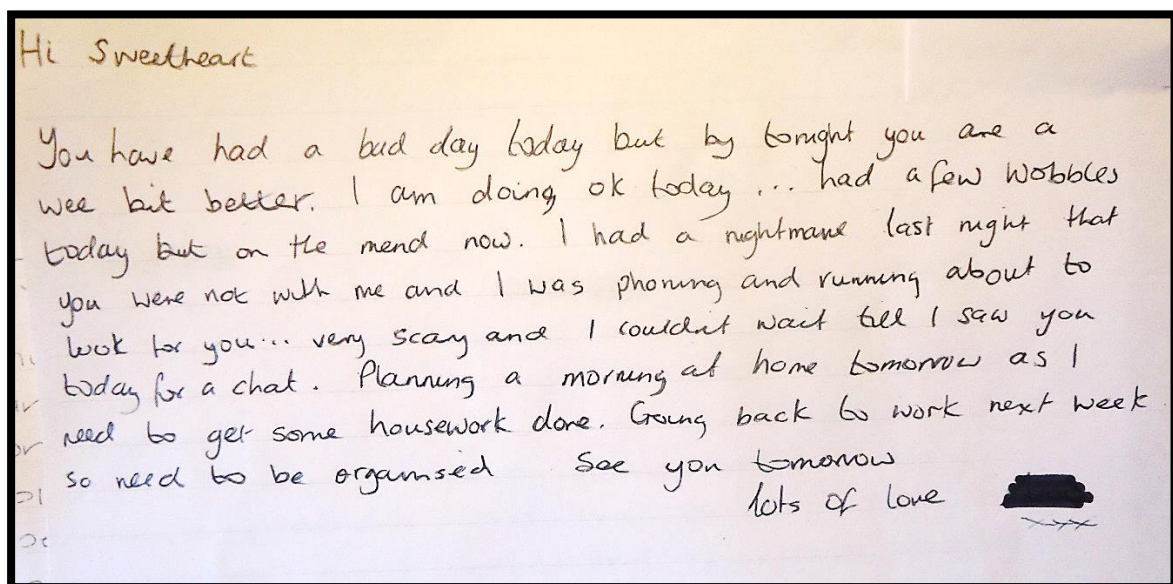
The theme emotion relates to emotion present in the diary and emotion experienced or associated with using the diary. Emotion is present in the diary mainly in the form of entries written by family members. Emotion associated with using the diary, referred to as emotional effort, can occur from reading or writing diary entries.

Three sub themes were identified in the theme emotion: *emotional effort*; *emotional support* and *attachment to the diary*. Emotional effort explores the emotional effort or effort associated with reading and writing a diary, experienced by nurses, family members and patients. Emotional support relates to the emotional support

experienced by family members and patients from writing in and reading the diary. Attachment to the diary is when family members and patients become attached to the diary, evident in the way the diary is used and kept after the event.

#### 4.5.1 Emotional effort

Emotional effort illustrates the emotional effort or effort associated with reading and writing a diary. Emotional effort is experienced differently by family members, patients and nurses during and after the time in ICU and therefore each group will be looked at separately. As previously discussed, family members are invited by nursing staff to write in the diary (*see 4.3.1 Content of Information*). Encouraged by nurses, family members often write about what they are thinking and feeling, as seen in the following diary excerpt from a patient's wife.



**Figure 22: Family member 'thoughts and feelings' diary entry - P1**

Entries from family members and nurses appear consecutively throughout the diary therefore it is easy for nurses and family members to access the diary and read entries that have been written while the patient is in ICU.

### Family member's emotional effort

Family members often used the term 'emotional roller coaster' to describe what it was like having a loved one in the ICU. When it came to reading nursing entries in the diary family members reacted in different ways, depending on what had been happening with their loved one and how they felt at the time of reading the diary, as one family member explains.

*It'd just depend on how she (mum) was, how ah felt about what the nurses wrote in it. Because it's terrible tae say but see if she didnae have a good night 'ah dinae feel happy so ah dinae like what the nurse wrote', if you know what ah mean. But, if she had a good night an ah did feel alright in myself ah would like what the nurse wrote. Ah think it depends a lot on your own frame of mind as well as what you're reading, d'you know what ah mean. Some of the stuff could quite easily get your back up if you're in a bad place or something you could laugh at if you're in a good place. It just depends on the individual's frame of mind ah think...*

*...it's a horrible emotional roller coaster when you've got somebody in there. So in my personal experience it's just how ah felt when ah read it whether ah wanted tae hit them or say "thanks very much" (laughs). (Katrina FM4)*

Therefore, the emotional effort experienced by family members, from reading nurse entries in the diary, could depend on where family members were on their own 'emotional roller coaster'.

When it came to writing in the diary there were reports about some family members being unable to write because they were too upset or did not know where to start.

*Ma parents won't write in it. They, they just point blank refuse tae cause as ma mum says "ah don't know where tae start." (Angela FM1)*

*I had tae put wee bits in it for her. She said "just you do it mum" she was too upset to do anything...she just said "put a wee bit in telling dad ah love him" that was all... (Heather FM2)*

Patients had further insight into how their families coped with the diary.

*Ah think one of ma daughters found it, she said she didn't, she didn't write much in the diary. She couldn't, she found it difficult to write something in the diary. Where the other daughter did, ma wife did, ma sister an that did, an ma cousin did. So it's, it's a help tae those that*

*want tae write in it sometimes, an it's hard for others tae write in it.  
(John P1)*

*Julie her sister found she couldn't write in the diary cause she was really  
quite upset. (Graham P6)*

Nurses were mindful of what family members were going through and tried to find the right time to introduce the diary, as one nurse explains.

*Ah would just kinda gauge by how, how they're reacting with things and  
ah would maybe leave it a wee while you know till near the end of  
visiting or if they were coming in later at night an then approach them a  
bit later on. Ah wouldn't kinda bamboozle them all at once with this, this  
and this and here's a diary to write. Ah would, ah would leave them a  
wee while tae come tae terms with what's happening and then ah would  
explain what it's for, would they be interested in taking part an ah think  
most of them say yeah. (Valerie N3)*

Most family members participated in diary writing and some even experienced emotional support from using the diary, which will be explored in the sub theme Emotional Support (see 4.5.2 Emotional support). However it would appear that the emotional status of family members in the ICU may influence how they interpret what has been written by others and whether they are able to write in the diary or not. Thus, using the diary requires a certain level of emotional effort from family members.

### **Patient's emotional effort**

When patients read the diary for the first time it was often an emotional experience and could take a while to get through all the entries, as one patient recalls.

*It sat up beside ma medicine in the kitchen an it sat there for ah, ah  
would say a good few weeks after ah got home. The first time ah opened  
it there was nobody else in the house an ah lifted it and ah opened it and  
ah read the first page. The tears were in ma eyes and ah just shut it and  
put it back. An then it was two or three days before ah went back to it an  
sat down and actually physically read some more of it an then ah had it  
all read but it, it (voice strained), it hits the heart strings. (John P1)*

Reading about what happened combined with what family members had been thinking and feeling was quite a shock for patients and evoked mixed emotions.



*...ah had smiles and tears. Sad tears, happy tears...shock as well.*

*The mixture of feelings ah had was just, my god, unbelievable. It was. There was fear, there was gratitude, there was so many emotions in there. Ah can't remember. At the time, you know how your mind just goes buzz, that was me and it took me to the next day before ah could look at it again (Alison P4)*

Patients gained an insight into what family members had gone through during the time in ICU.

*...it was how your family's feeling, what they go through. Cause ah mean Angela would say "we went through all this when you werenae here, we went through it with you". An you don't realise until you read the diary just how bad it was for them as well, as a family. (John P1)*

*Aye they've been through a wee bit as well when ah wasnae here sort of thing, emotional for them as well. (Steven P2)*

A feeling of guilt was experienced by some patients in response to learning what their family had been through, blaming themselves for what happened.

*...ah just thought 'no way, what have ah done?'. That, that was devastating because ah remember ah lay down, ah still never slept but ah lay down afterwards and ma mind just kept birling it was like it was going all these different places at one time like 'what have ah done?', 'what have ah put them through?' You know just things like that, ah had no idea. (Alison P4)*

Building up to reading the diary could take time for some patients. The term 'mentally ready' was used. One patient, who already knew about diaries from a previous experience, reported being unable to look at his diary for a few weeks because he was having flashbacks and worried that the diary would make these worse.

*Ah must admit, after ah came out of hospital ah couldn't look at this diary. Ah couldn't physically, you know. Ah couldn't get in the way to go and have a look at it cause these flashbacks and things were happening an ah thought 'this will just make it worse'. Ah didn't look at it for, it must have been two or three weeks. (Graham P6)*



The diary brought back to patients what happened, making them re-visit the time when they were critically ill. For one patient, this was quite frightening and although he read his diary as soon as he was given it in the hospital and frequently referred to it at home, he deliberately tried to block out certain information as it upset him (*see 4.3.3 Interpretation of information*).

*Aye it's emotional but it gets you thinking what you actually went through and when you read some things, but ah block that bit out cause ah don't want tae know to be honest with you (laughs), ah try and block that part of it out. Ah just don't want tae think about it anymore (Steven P2).*

Family members were aware of the information the diary contained and were sometimes worried about how their loved one would react or cope with reading this, as one family member explains.

*...ah think 'oh what if he reads that', an then ah think 'well he's not, he'll not read it right away because he won't want to'. Ah know he won't want to and by that time he'll be completely better and it'll be fine (Jean FM6)*

Other family members suggested it would be better to read the diary together for the first time and did not want their loved one to read the diary by themselves.

*Realistically ah wouldnae like her tae go through it herself cause a lot of the stuff in it is really quite scary. So it'd be nice if the two of us could sit doon an go through it... (Katrina FM4)*

However, it was not always possible to control when patients had access to the diary, despite a small team of nurses co-ordinating and handing over diaries to patients. One patient spoke about what it was like reading her diary in ICU before it had been handed over, having found it at the end of her bed after seeing family members and nurses writing in it.

*An am looking, thinking, and going "how?" An the tears were tripping me with frustration. But when ah read that first entry fae Katrina saying 'as you know I got a phone call at 02:30...' an am like "what the fuck?!" Ah just thought "eh?!", "what, what's been going on?" an at that ah stopped at that. That just sent me reeling because ah had no idea what had been going on an then of course ah read wee letters from ma*

*granddaughter and all that an it just brought everything crashing...they were writing fae the heart how they were feeling at that time. (Alison P4)*

Therefore, reading a diary without any knowledge of what had been happening and what information people might have written in the diary could make what was likely to be an emotional experience for patients even more distressing.

Emotional effort for patients came from reading what had been written in the diary. Patients gained an insight into what their family had been through as well as learning about how unwell they had been. All the patients interviewed found this to be an emotional experience, especially the first time they read through the diary, and spoke about being mentally ready to read the diary. Emotional effort associated with reading the diary is different and individual to each patient. For example, one patient felt guilty having read what her family had been through whereas another patient deliberately avoided sections of his diary that frightened and upset him.

### **Nurse's emotional effort**

The experience of reading entries in the diary, containing the thoughts and feelings of family members, was discussed by most of the nurses interviewed. Nurses used words such as 'hard', 'upsetting' and 'emotional' to describe what it was like for them to read entries from family members.

*Ah think when you see the family entry that can kinda be a bit upsetting sometimes. If it's maybe like a kinda couple or something, you're reading what their loved one's writing in. How much they miss them and they just want them home or they really hope that they're gonna pull through, an that can be quite hard sometimes. (Carrie N2)*

Nurses were exposed to what family members had written when reading the diary or when writing entries to the patient. One nurse found it particularly upsetting to read diary entries from younger family members.

*If it's younger members of the family, if they're writing to their dad that can be really quite upsetting for us, you know. They just want them to get better. You feel you can actually pick out the despair...that they just want their dad back and better, or their mum, or whatever and it can be quite hard to read you know but you don't automatically go and read that you just, you just have a wee look and you think 'that's not very pleasant', but that's just a personal thing. (Jim N6)*

An example of a younger family member writing in the diary can be seen in the following diary excerpt.

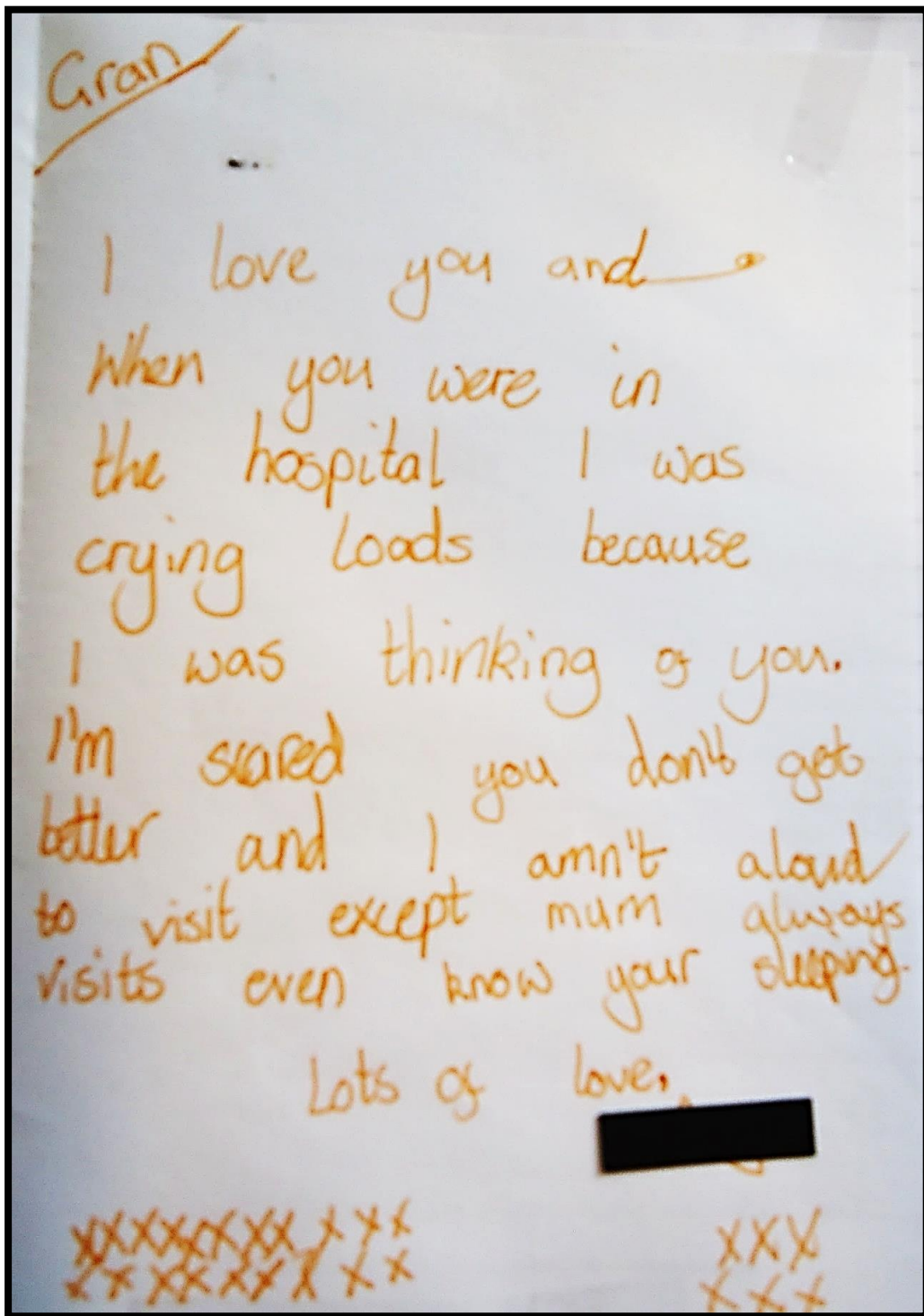


Figure 23: Family member 'child's thoughts and feelings' diary entry - P4

The child who wrote the diary entry was not allowed to visit her Gran in the ICU. Therefore, it became apparent that nurses were able to read entries from family members who were not present in the ICU as well as those who were.

Reading what had been written by family members made the situation ‘real’ for nurses who tried to emotionally detach themselves, explained by one nurse.

*...reading the relatives account can be quite hard cause ah think working in ITU you can completely detach yourself from the situation cause you have tae, an so sometimes if you go and you read you know like, like a mum or a wife or something you're kinda like that "oh..." Cause it brings it back to you the fact that that person belongs tae somebody. D'you know that way that it can be a bit upsetting, but it's not a bad thing cause it does make you think d'you know. Although you are totally, still totally detached from it, which is a terrible thing to say, but you know what ah mean like after so many years you kinda stop getting upset about people, which sounds really bad, it does sound bad. Em, but it's quite a good thing to take you back to the fact that you know, making it a bit more real ah would say (Beth N4)*

Although it could be upsetting to read what the family were thinking and feeling nurses did not necessarily view this as a ‘bad thing’ and were able to accept what family members had written, as one nurse explains.

*Ah think you just deal with it because it sort of brings you back down to earth, because this person here who is ill is obviously a father and he's got responsibilities and what not...you know and that's, that's not a bad thing. (Jim N6)*

However, nurses had to ‘deal’ with what they read in the diary and acknowledged that if they spent too much time thinking about the ‘real’ situation then they would be unable to do their job properly, as they would be too upset.

*Ah do remember one girl that we had an it was very sad to read because her husband was writing, or her partner was writing, like how much he missed her an you know all they sort of things. So it can be a bit of a tear jerker at times as well. Ah just kinda, feel it here (in my heart). 'That's a shame...' , 'that's really nice of them to write that...' Em just try not to dwell on things like that too much, too much of a tear jerker (laughs). Otherwise we'll all be going, going about crying (laughs). (Valerie N3)*

Therefore, nurses developed ways of coping with what they read in the diary as described in the above example, '*...try not to dwell on things like that too much...*'.

In addition to the emotional effort associated with reading what family members had written, nurses found it difficult to know what to write to patients and felt bad when writing about certain events in the diary, as one nurse explains.

*Sometimes ah think it's quite hard what to say especially if somebody has been restless...you sometimes feel a bit bad writing things like that...  
(Carrie N2)*

Knowing that the patient was likely to read the diary at a later date, nurses did not want to upset or worry patients with what they had written.

*...you think 'oh how am ah gonna write that in the diary?' So that they don't get, you know too upset when they read it. It's quite difficult sometimes just finding the right words just tae explain it without worrying them too much... (Valerie N3)*

Therefore, in addition to the emotional effort experienced by nurses when reading entries from family members, emotional effort was an issue for nurses when writing to the patient about difficult situations occurring in the ICU.

#### **4.5.2 Emotional support**

Emotional support from the diary is experienced by family members and patients.

Unlike the experience of emotional effort, nurses did not experience emotional support from using the diary. Whereas family members who experienced emotional support gained this support through writing and reading the diary in the ICU.

Emotional support for patients came from reading the diary and keeping it at home during recovery.

##### **Emotional support through writing in the diary**

Emotional support through writing in the diary is specific to family members during the time in ICU and will be discussed as two separate processes: *writing about thoughts and feelings* and *the act of writing*. The role the diary plays in supporting family members emotionally is quite significant and spoken about by nearly all of the family members interviewed however there appear to be different mechanisms for

how the diary provides emotional support through writing, therefore these have been separated to try and illustrate this more clearly.

*i. Writing about thoughts and feelings*

Writing in the diary was viewed positively by the family members interviewed, as one family member explains.

*Ah think ah thought it would be a good thing because ah quite believe that by writing things down that its part of your healing process. Em, but it's not something that ah would probably have done myself. (Angela FM1)*

Family members used the diary to write about their thoughts and feelings, having been encouraged by nursing staff to do this when their loved one was admitted to the ICU. Writing in the diary meant that the diary worked differently for family members in comparison to patients, as explained from a dual perspective.

*The diary, my diary, personal diary just kinda em, made me realise how ill ah was and how worried everybody was about me and how much the nurses did. That's what that diary did for me, my diary. Graham's diary em, for me was a way to express how ah was feeling when he was ill. (Jean FM6)*

As explained, the diary gave Jean a way to express her feelings when her husband was in ICU which was a common finding amongst other family members interviewed. The diary offered family members a space to disclose thoughts and feelings (emotional information) that could be shared with the patient at a later date.

*...ah thought 'well its good you kin put your thoughts on the diary then an he kin go back an read it' ...it made you feel a wee bit easier. (Heather FM2)*

A positive change in how the family member felt from writing about their thoughts and feelings suggests this process can offer emotional support to family members. Furthermore, family members reported using the diary, for emotional support, to get their 'emotions out'.

*Ah think for me its therapy, to get it, to get your emotions out. (Angela FM1)*



The experience of getting emotions out onto the pages of a diary through writing was described as 'getting it off your chest' and feeling like 'a weight had been lifted'.

One family member explained in detail her experience of having a loved one in ICU and writing in the diary.

*It was great because it felt like you were getting a lot off your chest. You know what ah mean with ma dad no being here anymore an then ma mum lying here ah don't have any parents, av no got a partner and ah was like, ah thought ah was gonna burst. Cause you know you've got aw that inside you. The first night ah wrote in the diary ah think ah wrote about two pages an see when ah left here ah felt like 'that's good'. You feel like you're getting it oot when you write it doon...*

*...to write it doon ah felt, ah felt lighter aye...an ah didnae need tae burden anybody with the problem. (Katrina FM4)*

Furthermore, Katrina referred to the diary as her 'saviour' as not only did writing in the diary make her feel good it also helped to stabilise her mood when visiting and prepared her for future visits to the ICU, as explained in the following quote.

*...you had aw this pent-up agitation an frustration, an you waited to three o'clock coming everyday tae see her, an you were really ratty by the time that came. Then when you write it doon an you walk away an you just feel 'that's better', an you were ready for the next visiting, do you know what ah mean. But ah liked it, it did it saved, it really was, it was ma saviour, really good. (Katrina FM4)*

Writing in the diary gave family members an opportunity and a way to express their thoughts and feelings. However, it was suggested by one nurse that not all family members needed to use the diary in this way and for some people this was not how they would choose to express themselves.

*...they weren't obviously the kinda people who needed it. D'you know they were just more focused on their relative eh an maybe just not people who expressed their emotions that way or express anything that way. (Jane NI)*

Therefore, how the diary was used by family members in the ICU depended on the family.

*Ah think some families use them as a coping mechanism and ah think some families don't. Ah think it's up to the individual family. (Fiona N5)*

Nevertheless, when the diary was used to express thoughts and feelings or 'get emotions out' it appeared to have a positive effect on family members, their emotional well-being and their ability to cope with the reality of having a loved one in ICU.

Another issue raised was the common belief amongst family members that the diary was meant for the patient and not them. Therefore, family members struggled to accept that they could use writing in the diary for support, even when support was experienced.

*It wasnae for us we were writing, it was for her. It was therapeutic for us ah suppose, as a release of what was happening and where we were, an the environment we were in. (Lynn FM3)*

Nurses acknowledged that writing in the diary helped some family members however at the same time there was a concern about how patients would react when reading what family members had written, as one nurse explains.

*The relatives can sometimes express themselves better, in the diary. It lets them get a wee bit off their chest you know. Em, if they're struggling to cope as well they can sometimes put it down. Em, which isn't always a good thing when the patients go back to read them! But at the time it helps, it helps them. (Jane N1)*

Writing to the patient in the diary about thoughts and feelings during the time in ICU has already been referred to in this chapter as a way of communicating the unspoken word (see 4.4.3 *Communicating through the diary*). As demonstrated with the unspoken word patients do not always appreciate or value entries family members have written. Therefore, although emotional support may be experienced by family members from writing about thoughts and feelings this does not necessarily translate into emotional support for patients when reading the diary.

## *ii. The act of writing*

The act of writing in the diary, regardless of content, gave family members something to do when they were visiting in the ICU.



*It helps to give them something to do. In some way even vent their anger, or ah dunno just to kinda write their thoughts and feelings, or just write a lot of rubbish. (Beth N4)*

One family member describes the way she wrote at times, giving an example of how family members can physically ‘vent their anger’ or frustrations through the act of writing in the diary.

*It was great tae have it there and be able to just spill everything. Aye it was really good. Just write it all doon...scraping the paper cause you’re so fricken angry! (Katrina FM4)*

The act of writing helped family members cope with being in the ICU environment, even family members who were already familiar with this environment.

*You sit, you’re calm because you know it. You know, ‘ah know this situation, ah remember this noise myself’. Em, but the longer you stay the more agitated you become and so you write. You, you have nothing else to do but write in the diary. You don’t, you can’t actually do anything else but it, but do that an so that’s why am saying that it helps both sides (Jean FM6)*

Writing in the diary acted as a distraction from what was going on around the family member in ICU, which they had no control over. It helped to pass the time and gave family members something to do when there was nothing else to do but worry.

*When ah didnae have the diary ah was just sitting there looking at her an just kept thinking ‘oh my god what’s gonna happen to you? Look at you lying there, look at all they tubes, look at all they wires an these machines, an this thing breathing for you...’ But when you’ve got the diary an you’re blethering you don’t tend tae think about it the same. (Katrina FM4)*

Encouraging family members to write in the diary allowed them to contribute to what was happening and by taking on this role family members were more involved and given a purpose, as one nurse explains.

*They quite like writing in the diary, it gives them a sense of purpose too. Something to do rather than just coming in, you know looking at them (the patient). It kinda involves them a bit more rather than just sitting there looking at them, looking at the monitors. You know it gives them something tae focus on an do a wee bit of writing. And maybe they feel*

*as though they've done their bit, you know they've done a wee bit for them (the patient) while they've been in hospital. (Valerie N3)*

Writing in the diary moved the focus of family members to the future, therefore moving away from the reality of the present and towards the patient recovering at home from their critical illness.

*It was a focus you know. It was something to focus on because it was something for the future. At that point we didn't know what the future was gonna bring an as ah said earlier you know even if she hadn't made it, it'd have been nice to have had it because it was all oor thoughts at the time... (Lynn FM3)*

However as mentioned the future remained uncertain. Despite this the diary was viewed positively as a record of the family's thoughts and feelings during the time in ICU and was something that could be kept regardless of the patient's outcome. With this in mind the above family agreed to participate in the act of writing.

Writing in the diary did not offer emotional support to nurses however, what nurses wrote and how they wrote meant a lot to family members and patients and will be discussed further in the following section on emotional support through reading the diary..

### **Emotional support through reading the diary**

Emotional support through reading the diary was experienced by family members and patients. Family members experienced support from reading nurse entries in the diary whereas patients experienced support from both family member and nurse entries.

Although nurses were writing to the patient it became apparent that this could have a direct or 'immediate' effect on how the family member was feeling when they visited.

*Ah know that they're set out for the future you know. So somebody, the person that they're really aiming to have this diary is not gonna read it...could be for weeks or months later but the immediate effect from families that go into visit, it's got an immediate effect. (Jean FM6)*

One family member, who struggled with going into the ICU to visit her husband, found that reading what the nurses had written made her *'feel a wee bit easier'* and helped her *'cope a wee bit better'* as she was able to see the progress he had made.

*It helped me cope a wee bit better...ah must say it did. Because you were walking in everyday and you thought you were walking intae horror. You know, till you read that an you realised he had improved. Ah mean some days you were walking in an you would think 'no change in him yet'. But, when you read the diary, the girls (nurses) had put the changes that they had seen on him. So that kinda made you think again, you take another thought and think 'no well he must be improving' you know they wouldnae write that if he wasnae... (Heather FM2)*

Another example of the *immediate effect* the diary had on a family member is seen in the following quote.

*Ah mean there was some days ah would go in there feeling really, really alone and read what one of the nurses wrote, an it totally lifted ma spirits. (Katrina FM4)*

Having a record of people's good wishes and thoughts meant a lot to family members, as one family member explains.

*It's nice to get the kinda good wishes an the nice thoughts from everybody round about. Ah know that's what you would expect but it's nice tae have it, to see it on paper. D'you know and how far he has come an how well he is doing. It just kinda reinforces it for me that he is doing well. (Angela FM1)*

Furthermore, reading what nurses had written reassured family members that nurses cared and were doing everything they could to help their loved one.

*You know you read some of them and they're so caring. You know and they're so 'we tried to do this but...' it's like 'ah was so disappointed ah wanted you to be able to do this but never mind we'll try it again tomorrow'. You know so instantly from my point of view em, being a visitor and am a wife, it was very comforting to me. (Jean FM6)*

However, the emotional support family members received from using the diary and the need to use the diary became less important as the patient was recovering.

*Ah think when ah was going through it, it (the diary) was ma best pal if you like. Now ah think it's more tae help ma mum... Ah can honestly say if ah was tae read it noo ah don't think it would dae anything for me personally but ah think it will help her a lot. (Katrina FM4)*

Emotional support for patients came from reading what family members and nurses had written in the diary while they were in the ICU. Patients reported feeling happier knowing what happened and who had been looking after them, as one patient explains.

*The stuff that they wrote was very informative and made me feel a lot happier. So it eased any anxieties ah had cause ah was quite anxious when ah came back (home), cause ah wasn't sure what actually went on initially.*

*It was nice to know who was actually looking after me, like ah felt that quite comforting. It's nice you know, they've signed their name and put little happy faces on. It was nice, it made me feel, it made me feel good. (Graham P6)*

The detail nurses put into signing and personalising their entries was appreciated by patients and added to making the diary more personal to the patient.

Patients liked to have a record of who had been visiting or phoning when they were in ICU, as often they couldn't remember this. This was quite significant for one patient who had an entry written in his diary from a friend he had not seen for a long time.

*Ma mate ah haven't seen for a long time he appears, writes something in the diary, so ah can reflect on that when ah see him. (Steven P2)*

Additionally, patients learned how much people cared about them, explained by a family member who had previously been a patient in ICU.

*It's nice to know that all your family care so much about you an the nurses were working so hard. (Jean FM6)*

Nurses intentionally wrote words of encouragement and well wishes for the patient to support them during their recovery, as explained by one nurse.

*Ah also try and put a wee bit of you know... 'keep up the good work', 'keep things going' just so that they know you're working with them every day. You know just so that they can look back and say 'oh well they were trying tae help me get better!'*

*...we are quite light hearted at the end of it, we all kinda try tae gee them on. (Jane N1)*

Patients valued having well wishes and thoughts written in the diary, in the same way family members did, as this was something that could be kept and referred to at a later date. One patient in particular spoke about returning to sections of his diary for ongoing encouragement and support as it gave him a 'boost'.

*...there's some comments in it, kept you going...*

*...people saying 'get out', 'get well soon'...*

*...av picked it up a few times an read through it an it's gave me a wee boost... (Steven P2)*

Patients and families receive emotional support through reading the diary. The diary is written to the patient however family members experience emotional support indirectly from what nurses have written. Nurses and family members give support to patients through writing words of encouragement and well wishes for the patient to read during their recovery. Furthermore, patients may return to their diary multiple times for support.

#### **4.5.3 Attachment to the diary**

Family members and patients reported becoming attached to the diary. Family members looked for the diary as soon as they came into the ICU and the diary became part of their visiting routine, as one family member explains.

*You came in and you automatically just lifted the diary...It was like "oh where's the diary?" It was the first thing we all looked for. It was part of the routine that we all kinda had. Ah know that a couple of days folk had come oot an they've says "oh av forgot to write in the diary". You know an they were quite annoyed that they forgot to write in the diary. (Lynn FM3)*

When patients moved out of ICU the diary did not routinely go with them, it was kept safe in the ICU until handed over to the patient. Family members still looked for the diary and could not understand why it was not there, as one family member explains.

*When she (mum) woke up ah thought ah would like a wee look at it and it wasnae there, it was gone. Somebody had took it away. Ah don't know where it is or what's happening with it but it was gone. Cause ah said tae her "where's your diary?" an she says "ah got a wee look at it last night but it's away". Am like that "where is it?" Cause ah just thought 'sh...sugar' cause it's dead soppy stuff av put in it, am going "who's reading that?" (Katrina FM4)*

Learning there was a diary and then not having access to it generated strong feelings amongst some family members and patients. For example, one patient who was discharged home before receiving her diary explained what this was like.

*Ah remember feeling cheated, ah remember thinking 'that's mine, ah want tae take that home with me'...it took a wee while to come out, an ah remember thinking 'where's ma diary, where's ma diary?' (Alison P4)*

All the patients interviewed spoke about keeping their diaries and whether the diary had been read once or several times just knowing it was there was comforting.

*Ah will read it again but ah haven't. It sits, it sits there and it'll always be in the house, that's one thing but ah will read it again. (P1 John)*

*Ah knew it was there, ah knew ah could go back to it and read it again. (Steven P2)*

The diary was kept somewhere accessible at home, for example in the kitchen or on a bookshelf. One patient who planned to keep her diary spoke about eventually putting it away.

*I'll put it away eventually but am no ready. Like when ma husband died it took me about a year and a half to clear his stuff oot. So it still sits there as a wee reminder an av seen me just sitting through in the kitchen an opening it up an not reading it as such but it's just there, it's there, it's ma pal! (Alison P4)*

Comparing the diary to her late husband's belongings and referring to it as her 'pal' indicates how much the diary meant to this patient and that coming to terms with what happened would take time.

Additionally, the researcher observed a final activity performed with a diary by nurses in the ICU, which demonstrated the significance of the diary to one family member.

*The nurse asked her student to get a poly bag while she wrote some final words in the diary at the nursing desk. Another nurse asked "...what are you doing with that diary?". The nurse explained, as she closed the diary and placed it in the clear poly bag, handed to her by the student nurse. "His sister wants the diary to be buried with him." A knot was tied carefully in the bag and the nurse lifted the cover off the mortuary trolley, exposing a white sheet underneath. The diary, now contained in a clear plastic bag, was placed on top of the body wrapped in the white sheet. Having already asked the porters to wait while she organised this, the nurse then instructed the porters that the diary was to remain with the body until collected by the undertakers.*

*Observing this 'final act' with the diary was surreal. I remember thinking "...what is it about these diaries? They must mean so much to people...", as demonstrated by this final request for the diary to remain with the deceased person. On questioning the nurse later, she commented "...you can see why some families use it as therapy or how it might be therapy..." (O-04 Final Diary Act in ICU - CM fieldnotes)*

Although the evidence was limited, attachment to the diary was demonstrated in accounts presented by family members, patients and from the researcher's own observations. Family members reported looking for the diary when they came into visit in the ICU whereas patients kept the diary at home so that they could access it easily.

#### **4.5.4 Summary**

The theme emotion highlighted two main contrasting experiences associated with the diary, emotional effort and emotional support. Family members, patients and nurses experienced emotional effort with writing in and reading the diary, however there were differences between the groups. Family members experienced emotional effort from writing in and reading the diary in the ICU, with some family members unable

to write as they were too upset and others reacting to what they read in the diary. The emotional status of family members at the time of interacting with the diary appeared to influence their experience. Whereas with patients it was acknowledged that reading the diary after being in ICU would be an emotional experience, as through reading the diary patients found out how unwell they had been and what their family had gone through. The first reading of the diary was the most difficult and therefore patients often did not read their diary until they felt mentally ready. Nurses experienced emotional effort with the diary from reading diary entries written by family members and from trying to write about difficult situations in the ICU.

Emotional support from interacting with the diary was only experienced by family members and patients. Family members gained emotional support from writing about their thoughts and feelings in the diary, from the act of writing and indirectly from reading what nurses had written to patients. Whereas patients experienced emotional support from reading the diary which contained words of encouragement and well wishes for them to read during their recovery. The diary was often read on multiple occasions by patients for support after ICU. Furthermore, patients and family members reported becoming attached to the diary with family members looking for it when they visited and patients keeping it in a safe place where they could find it. Finally, in addition to there being differences between groups and their emotional experiences associated with the diary there were also differences between individuals.

## 4.6 Person centered

ICU nurses care for patients and their families in a highly specialised technical area. The theme person centered explores how the use of diaries can promote a more individualised and person centered approach towards caring for patients and families in this environment.

Three sub themes have been identified: *diary as part of care*; *making an effort* and *identity*. Diary as part of care explores how the diary is viewed as part of the care provided by nurses in the ICU. Making an effort is concerned with nurses taking the time to write in the diary and how this is viewed by family members and patients.



Identity relates to the identity of those who write in the diary and those who the diary is written for or about.

#### 4.6.1 Diary as part of care

The sub theme diary as part of care explores how the diary is viewed as part of the care provided by nurses in the ICU for patients and family members. All the nurses interviewed had worked in the ICU before diaries were introduced. One nurse explained what he thought when he heard about the use of diaries in ICU.

*My initial thoughts were I thought it was a bit Cinderella ICU...to me ICU's always been a technical area. It's been very you know forward pushing in medicine and what not. You know the diaries seemed to be part of ICU that we hadn't previously looked at in any great detail, especially within the late nineties you know cause ICU was very much geared towards technical patient care...*

*...Cinderella ICU, it's a bit kinda arty. It's not, it's not the ICU to me, that's more of a science, but this is more of an arty aspect of it... (Jim N6)*

Referring to an ICU with diaries as a 'Cinderella ICU' suggests that diaries are a less technical or scientific aspect of care. Nurses made a distinction between diaries and the more technical or 'physical' aspects of care, however as one nurse explains.

*...it is as important as the physical aspects of care because it's what's gonna help their recovery eventually once they get there. (Fiona N5)*

Family members and patients accepted the diary as part of the ICU 'package' and 'took it for granted', as illustrated by the following quotes.

*It was just like a tool. It was just something that was an accessory if you like that came with the package. (Lynn FM3)*

*Angela (wife) told me about it and ah just took it for granted to a certain degree that that's what happened in there. You know av never been in there...just took it for granted more or less aye. (John P1)*

Writing in the diary was a regular activity undertaken by nurses working in ICU, as one nurse explains.

*...we write in it every day until the patient gets discharged. (Beth N4)*

Nurses viewed writing in the diary as part of their work in ICU and tried to incorporate this into each shift.

*...you would try and build it into your day at some point to write something. (Jim N6)*

*...from speaking to staff informally about my research it is apparent that diaries are very much part of the care they provide for patients in this unit. As with other equipment used to provide care, diaries are kept in the unit in an accessible place, at the nursing desk. Once the decision has been made to start a diary the diary is then kept at the patient's bedside until the patient leaves the unit. Nurses report trying to write in the diary each time they are on shift, however this activity tends to happen later on in the day once other needs have been met such as personal comfort or in between any planned procedures including medication administration and hourly observations. ('Diary Practice in ICU from informal conversations with nurses' CM fieldnotes)*

Some nurses reported that the diary did not change or make any difference to how they cared for patients however writing in the diary was valued as an important aspect of care.

*Overall ah don't think it makes any difference to how ah actually care for them, but ah try to make sure the diary it's part of that care now. Eh it's very much if av got a ventilated patient it's on ma mind that before ah go off ah have to write something or ah want to write something, particularly if it's a new admission or if somebody's not written anything for a few days. Not all nurses are pro diary so there's been a couple of days where nothings been written you know. I'll make a point of making sure that something's been written in... (Valerie N3)*

Providing a diary as part of care in the ICU is dependent on nurses starting a diary for patients admitted to the ICU and writing in the diary on a daily basis until the patient is discharged. However as mentioned not all nurses were 'pro diary', meaning that some nurses did not participate in diary writing and days were missed.

When diaries were introduced into ICU, one of the main concerns nurses expressed was that the diary could potentially be used as 'a legal document' in a court of law, a nurse from the diary team explains.

*At the beginning it was terrible. People didn't believe in them, didn't want anything to do with them, were scared to write in them in case it was you know "a legal document". An you're trying to explain "it's not a legal document". So you have people who just refused, who just ignored them. D'you know "I'm not writing in it", "I'm not having anything to do with it" and didn't explain it to families. Ah don't think there's anybody now that there's any issues with. I think they all kinda try and encourage the family and each shift write in, or every 24 hours at least... (Jane N1)*

It would appear from another account however that some nurses remained unhappy and uncertain about the legal status of diaries, choosing not to participate because of this.

*There are some nurses who are still here saying "no I'm not writing in it, I'm not doing it, don't think they're right, don't want tae do it". They still think that there could be a legal issue from it...if you have written something down and you have signed your name to it and you were on that shift and you were the nurse that was looking after them you can't deny it, it's there in black and white...*

*Some of ma colleagues believe that eventually a diary will be used for the wrong reasons and we'll be kinda caught out with it so ah think that's why some people don't do it. (Fiona N5)*

Whereas for nurses who did want to participate, the issue of having enough time on each shift to write in the diary was raised, as discussed in the following quotes.

*...if we have a busy shift we have all forgotten to write in it. (Jane N1)*

*...ah think for nurses it's just a time issue, everything's always time, we always have run out of time and ah think that's maybe why you don't write in them as much. If you've got somebody who's really, really sick, writing in their diary is not a priority (Fiona N5)*

Therefore, although the diary was valued and used as part of the care provided in ICU it was 'not a priority'. Despite this nurses were happy to dedicate time to writing in the diary where possible, as one nurse explains.

*Yes it takes up a bit of our time but if it helps them in the long run. I mean it's only a couple of minutes to write a few lines and if in the long term its gonna help the patient to recover, help them to put together*

*what's actually happened then it's worth those extra couple of minutes...  
(Valerie N3)*

Family members recognised how busy the nurses were and appreciated the effort and time put into writing a diary for their loved one, as one family member explains.

*Ah was quite pleased with what they had been writing, yeah. To be honest ah was quite pleased that they even wrote at all because they're very busy in that ward and they don't really have a great deal of time tae sit and write things. So ah was quite pleased that they even bothered to write cause a lot of them wouldnae have in the other wards, ah mean they really wouldn't have... (Mary FM5)*

The effort made by nurses to write diaries for patients during the time in ICU and what this meant to family members and patients will be presented in the following section (*see 4.6.2 Making an effort*). However as detailed in this section, introducing diaries as part of the care provided in the ICU involves a period of change and acceptance. It was suggested from one nurse that an ongoing concern with diaries in a minority of nursing staff existed, relating to the potential for legal issues to arise. In ICU, the diary as part of care is prioritised and defined in relation to other aspects of care provided which can be influenced by the daily workload nurses manage in this environment.

#### **4.6.2 Making an effort**

As discussed in the previous section, the diary was viewed as part of the care provided for patients and family members during and after the time in ICU. The sub theme making an effort is concerned with nurses taking the time to write in the diary and how this is viewed by family members and patients. Family members and patients placed great value on nurses making an effort by taking time to write in the diary.

*You know it wasn't a case of "hell av got to write in this diary". They (the nurses) wrote, you know, a paragraph every time so it's quite good to read it all and they did put an effort into writing the diary so that made me feel good as well. (Graham P6)*

Knowing that nurses were taking time to write in the diary meant a lot to family members, as demonstrated in the following quotes.

*...the comfort is not what, the information that's in it as much as the feeling that they've taken the time to write this down. (Jean FM6)*

*Ah don't think ah could ask for anymore from them. The fact that they took the time tae do it ah thought was really, really nice...ah was really touched, really touched. (Katrina FM4)*

Likewise, patients appreciated that nurses had made an effort to write something in the diary, even if it was quite small, as one patient explains.

*The nurses were lovely and they would just put a wee thing in ma diary just to say how ah was, some of them are just tiny an it's the thought that counts. (Alison P4)*

Using diaries in the ICU demonstrated a more 'personal touch' or approach to caring for the patient as well as involving family members, one nurse explains.

*Ah think when we bring the diary out they (the family) see it as more of a personal touch and they quite like it. They feel like they're being, you know it's not just being looked after from the technical aspect but there's also a huge personal touch involved in the diary as well, gets them involved a bit...*

*They get a feeling of being able to contribute something... (Jim N6)*

Providing the diary as part of care in ICU can potentially support family members by involving them through writing. The act of writing in the diary and the positive affect this can have on some family members has previously been discussed in this chapter (see 4.5.2 *Emotional support*). However, family members spoke about how nurses wrote in the diary and gave the diary a 'personal touch' or human touch by addressing their loved one directly through the diary.

*The nurses had been writing... 'you had a good night and I'll see you tomorrow'. It was the wee personal touch fae them that they were putting in it... (Lynn FM3)*

*...ah think there's a thing in there that says about '...ah was telling you a joke the day and you actually laughed!' Things like that you know so it makes it very humanised, instead of clinical... (Jean FM6)*

Nurses believed that taking time to write in the diary showed family members that the patient they were caring for was more than just a patient, as one nurse explains.

*...ah think probably reading what the nurses have wrote in the diary maybe make them feel as if their relative isn't just another patient, no matter if they are. Oh that sounds really bad! Ah think no matter if that's what we think you know, ah think it would probably make them think that the person that's looking after them does, like you know really cares about their welfare, because you've took the time tae contribute to the diary for them... (Beth N4)*

One patient in particular associated people taking the time to write in her diary with people caring, as explained in the following quote.

*Ah can't see any reason why somebody wouldn't want something like that because apart from anything else it lets them see that people actually care. Whether it be family, whether it be nursing staff doesn't matter it's the fact that people care. In this day and age that's rare, let's be honest. What's been written in there is personal to me and yes it lets me see that people care, they take the time to write something in that so yes they care. (Alison P4)*

However, as previously discussed there are various reasons for people not writing in the diary for example family members being too upset to write (*see 4.5.1 Emotional effort*) or as mentioned more recently nurses prioritising their workload (*see 4.6.1 Diary as part of care*). Therefore, not writing in the diary does not necessarily mean that people do not care however patients and family members appreciate people making an effort to write in the diary.

### 4.6.3 Identity

Identity relates to the identity of those who write in the diary and those who the diary is written for or about. Information written in the diary can give others reading it a better insight into the identity of the person it is written for (the patient) or the person writing it (the nurse or family member).

Through reading the diary nurses got to know the patient and their family.

*I'm quite interested to see the family's entries in the diaries, you can get to know the family as well and get to know the patient...you can tell a lot about a person when it's all written down.*

*...it just lets you know what they're like as a person. (Carrie N2)*

*You get to know the family...you get to know different things about the family, different things about the patient as well and it probably helps you to get to know them (Beth N4)*

Nurses noticed that family members often wrote about significant others in the patient's life as well as the patient's personal preferences and behaviours, one nurse describes.

*You can pick up a lot you know so if they've got grandkids or pets...whenever somebody's got a dog there's always a picture of the dog stuck in the diary, an the dog's got its own story!*

*...you pick up like funny wee things about the patients as well like their habits an things they like to do an stuff like that. (Beth N4)*

Getting to know the patient as a person and getting to know the family came from nurses gaining an insight into the patient, their family and life outside the ICU.

*If you have a wee read now and again it gives you an insight into the person's life...you build up a wee family picture of the family. (Jim N6)*

*It maybe gives you a better understanding of the patient and their home life. Em it maybe gives you a better insight into what the patient was like before they became ventilated and sedated...some families will write, 'the bowling club are missing you' or 'the golf club' you know an it just gives you a bigger picture of the person! (Jane N1)*

However, getting to know the patient in the ICU was still an issue even when a diary was being used.

*Depending on what the family have written it can give you a bit of insight into what kinda person they were, but having said that the family would probably tell you that anyway. If you say like she's been pulling at things or she's been trying to talk all day they say "oh she likes to chat..." You know so they quite often tell you things anyway about your patient. Ah believe you often feel you know the relatives better than you know your patient, until you have woken the patient up and can actually get to know them. (Valerie N3)*



Nurses relied on family members for personal information about the patient as family members knew more about the patient than the nurse, as seen in the following example.

*The nurses were asking us what she preferred tae be called, if it was “Alison or Ali” an ah says “ma dad always called her Ali so call her Ali” an like they would write that doon for her. ‘Your daughter said you prefer to be called Ali so av been calling you Ali the day.’ Ah just think that’s fabulous, d’you know what ah mean. (Katrina FM4)*

Whether personal information about the patient and their identity came through the diary or through discussions at the bedside, nurses were able to use this information to personalise communication with the patient and their family. As seen earlier on in the theme communication (*see 4.4.2 Facilitating communication with the diary*) general information written by family members was referred to by nurses to aid conversation with patients and families. Therefore, the identity of the patient and family was present in what family members disclosed through writing in the diary as well as through discussion with the nurse at the bedside.

When it came to nurses writing in the diary, consideration was given to the identity of the patient as a person.

*You think about, you know the person. Sometimes you reflect on, ‘this person has maybe been in the army, they’ve maybe been through a lot of life experiences’ an you respect that in someone. It’s not just someone lying sick. It’s someone with a wife, someone with a family, someone with a history, someone who has been through life and has a lot more life experience than a lot of us. So you know ah mean that obviously goes through your head. (Jim N6)*

*...you don’t know them personally, but ah think you have to gauge who you’re writing it too and what would be important to them. (Fiona N5)*

Family members appreciated that nurses made an effort to write a diary for their loved one in the ICU (*see 4.6.2 Making an effort*). However, the fact that the nurses did this without knowing the patient meant a lot, as one family member explains.

*I’m reading that they’re, that they’re shouting for him as well. Ah mean they’re, they’re putting lovely wee quotes in at the end of it saying that he’s done “really, really well” and they’re “proud of him” and for*



*somebody to not know, you know tae accept somebody that they've never met before and feel that for somebody... (Angela FM1)*

Another family member spoke about how the nurses wrote in her husband's diary and what this meant to her.

*They write things down in that diary that are like heart breaking. You could write a movie about them. You know they are so kinda heartfelt, what the nurses write, an it's not just 'oh I did this today and this is what you did today.' Ah mean they really, you know they, they pour a wee bit of themselves into there, what they write in the diary, which is really nice... (Jean FM6)*

The identity of nurses was present to a certain extent in the diary and as a result family members and patients were able to get to know nurses through what they had written. From a nursing perspective, having an identity in the diary meant that patients could get to know them which made the care 'more personal', as one nurse explains

*The care that I give can have a little bit more personal aspect to it cause they kin get to know me as well because obviously you introduce yourself as 'hi I'm Jim the charge nurse, I'm looking after you today' (Jim N6)*

Being able to identify and name nurses who had been involved in care during the time in ICU was reported by patients and family members to have a positive effect.

*It was nice to know who was actually looking after me...like ah felt that quite comforting (Graham P6)*

*Ah think it brought me and the nurses closer...you know when ah see their name. (Jean FM6)*

Therefore, patients and family members experienced comfort and a closer relationship with nurses from knowing who had been caring for them in the ICU and that nurses participated in writing to someone they did not know. Furthermore, nurses benefitted from reading about people in the diary, as this helped them get to know patients and their families when they were looking after them in the ICU.

#### 4.6.4 Summary

The theme person centered revealed the ways in which diaries contributed towards patients' and family members' experience of care in the ICU. Diaries were viewed as an integral part of care provided by nurses with some patients and family members taking this for granted. However, while there was an expectation that diaries would be provided, diary writing was not a priority and it was suggested that some nurses did not agree with this practice due to concern around potential legal and ethical issues with keeping a diary in the ICU.

Nevertheless, patients and family members appreciated nurses making an effort by taking time to write in the diary when they were busy and did not personally know the patient or their family. Through reading information in the diary, nurses gained an insight and got to know the patient and their family better, in addition to that learned from speaking to the family directly. Likewise, patients and family members found out who had been caring for them in the ICU with nurses introducing themselves in the diary and signing their name. This was comforting and enhanced the relationship family members and patients had with the nurses who looked after them. Therefore, the identity of those who wrote in the diary as well as those who the diary was written for or about was present in the diary.

#### 4.7 Gender

The theme Gender developed around male family members and diary use in the ICU. During informal conversations with nursing staff it was suggested that male family members were less likely to write in the diary when visiting than female family members were, an issue that was explored further in interviews.

*...ah think the male relatives are least likely to, to be participants in writing in the diary then what females would.*

**CM:** *and do you have any insight into why that is or...*

**Jim:** *Maybe it's a gender thing. Ah mean certainly when we speak to members of the family em it's easier to speak to females ah think to give news about patient's care than it is to males. It depends, but I normally find that a spokesperson tends to be a female, a daughter rather than a son. (Jim N6)*

When approaching male family members, I experienced first-hand the female ‘spokesperson’, having approached a son who immediately passed me onto his sister in law Lynn, referred to later on. Furthermore, there appeared to be a lack of males visiting in the ICU and trying to identify a male family member who was using the diary and willing to be interviewed was difficult, as recorded in the following field notes.

*From two male family members who were interested in participating, one (a husband) failed to turn up for interview, later declining and the other (a step father) was finding it difficult to cope so we agreed he could contact me when he felt able, however he discovered that his step son was unlikely to survive so we never made contact again.*

*When I approached the second male family member there was an uncle present who openly told me that he thought the diary was a good idea however he chose not to write in it because he wanted to be able to tell his nephew what he had to say when his nephew woke up rather than write it down on a piece of paper. He did not wish to use the diary to communicate with his nephew in this way although thought it was good and read entries in the diary when he went into visit his nephew. (‘Identifying male family members’ CM fieldnotes)*

To give the reader further insight into how a diary might be used by a male family member in ICU, the following example will be presented. Graham, although interviewed primarily as a patient, had previous experience as a family member in ICU where a diary was created for his wife Jean when she was critically ill. Jean refers to her husband in the following quote.

*He wrote in my diary yeah, yes everybody wrote...Graham was actually ill when ah was ill so he wasn’t here a lot but ma, it was ma two sisters that were here all the time, ma daughter, ma son so em they, they wrote more you know (Jean FM6)*

Graham wrote in the diary when he was well enough to visit Jean. Writing to his wife was a very personal thing for him to do and was not taken lightly, as he explains in the following quote.

*That diary is more personal than a normal diary that you’d write in because you know you’re actually talking about life and death things that are going on here (in ICU). That’s really quite, how should ah put it, it brings things to the forefront. It makes things very clear shall we say an*

*it also lets you know what people are, what people are thinking like your family and friends. (Graham P6)*

In addition to writing in the diary, Graham recalls finding the diary very useful, referring to it as a ‘tool’.

*It told you things that were going on when we (the family) weren't there and also gave us the opportunity to ask direct questions about things in the diary. You know because they'd wrote things, sort of like ah say not a lot of detail, and you would say "could you explain this bit to us?", "what was this going on?" an "what happened there?" So, it gave us a, a tool to use shall we say. It gave us an opportunity to ask and refer back to something rather than us say "what happened last night?" we could say "the nurse wrote this can you explain what actually that was all about?" We did that a few times so I found that very helpful, so that was good. (Graham P6)*

Once Jean was at home and recovering Graham spent time going through the diary with her.

*We'd go through it together. We've read it quite a lot, quite a lot cause Jean has no issues about going back. Cause when she remembers, Jean remembers her being in 'Jeanie land'. That's what we called it yeah, so we just, we just had a good laugh about that. (Graham P6)*

The way that Graham used the diary as a male family member was similar to how female family members have reported using diaries. So for example writing in the diary during visiting (*see 4.3.1 Content of information*), using the diary to support understanding of what was going on with his wife when she was in ICU (*see 4.3.3 Interpretation of information*) and reading through the diary with his wife when she was recovering at home. There was no mention however of the diary being used for emotional support during the time in ICU as has been reported by female family members (*see 4.5.2 Emotional support*).

Lynn, referred to earlier on as a female ‘spokesperson’, was not the direct next of kin however became the main catalyst for other family members writing in the diary, despite there being several male family members (sons).

*Ah think because I'd already heard about it anyway ah think it was easier for me. An then ah think just all the rest of them, ah just told them*

*tae write in the diary (laughs). Ah don't think they had an option it was "oh just write something!"*

*...you know every time ah passed somebody I'd be like that "mind and write in the book!" (Lynn FM3)*

Lynn was very close to her mother in law and had previous insight into diaries being used (for children in ICU) which may have motivated her to take on the lead role. Whereas in other families the decision to keep a diary was discussed between male and female family members and the one closest to the patient appeared to be the one others in the family looked towards for advice in making this decision, as demonstrated in the following quote.

*Jason says "you know her better than anybody, you two are thick as thieves" he says "what do you think?" ah says "aye ah think we should dae it" he says "right okay" (Katrina FM4)*

Despite the mutual agreement between Katrina and her brothers at the start, when it came to the reality of writing entries in the diary, her brothers found it difficult to 'see the point' in this activity.

*...ma brothers told me that...they personally didnae see the point, he says "ah felt like ah was writing about the weather an everything like that" (Katrina FM4)*

Therefore, the differences in gender and the roles undertaken in the ICU appear to extend to writing in the diary.

Male family members' involvement in the activity of diary writing was observed and reported by female family members.

*Ross had put something doon as well, ma oldest one, when he was in one day. Ah think it was just 'he came intae see her, it was nice and sunny and that was him finished up fae uni' and what no. Em, an ah know that Andrew and Faith an that had been writing in it as well and Chris he just put like 'what the girls had been up tae' an things. (Lynn FM3)*

Differences between what male and female family members wrote in the diary, in terms of the amount, detail and content, was explained by one male nurse.

*...if males write something they don't write as much but maybe that's the (male) way (laughs).*

*...ah think women elaborate on things. Whereas guys just 'hello I am so and so, I am here today, nice to see you, bye!' (laughs). Whereas women write about their day or some people (women) write about themselves 'Hi I've been out today, I thought I would come in and see you, I've been all over the place' you know 'the dog's missing you' kinda thing (laughs). (Jim N6)*

Reasons for not contributing to the diary were discussed by nurses and female family members. Nurses did not ask directly about diary use however comments were disclosed to them during visits from male family members, giving further insight.

*They've (male family members) never actually said, never actually said why they don't (write). Ah would never ask somebody why they don't want to do it cause if they choose not to do it that's their choice. But a few of them will say "oh hen ah don't dae the writing, am no very good at writing", or "ma spelling's really bad". (Fiona N5)*

Being able to write and having confidence in what you write appear to be important considerations for people wanting to use the diary and are not restricted to males or even family members. For example, a patient who wanted to write in his diary after being in ICU asked his wife to do this for him after trying to write a few entries himself.

*Well, he's just like says tae me "fill wee bits in it Heather for me, am not the best of writer" (laughs). (Heather FM2)*

For male family members age appeared to be a factor associated with writing activity, as one nurse explains.

*Male relatives, who are a bit older don't tend to write. Younger male relatives do write a bit but the older ones don't. Ah can't, ah don't know a cut off age but ah think maybe when, maybe when they get into their fifties an sixties they don't tend to write. If it's a wee old man an his wee wife's lying in bed then he doesn't tend to write much. Maybe his son might or his daughter. They, they'll be the main scribes in the diary but not, not the direct next of kin. (Jim N6)*

An observation made by another nurse may provide further insight into why older males 'don't tend to write'.

*...the older generation are really aware of their writing abilities. Does that make sense? A lot of older men. (Fiona N5)*

However, the age of the male family member or their ability to write does not necessarily determine who will write in the diary. For example, a younger and an older male in the same family never wrote in the diary at all.

*...ma grandpa never, ma younger brother never. They never said why. Em, ma younger brother, ma youngest brother's twenty one an he lasted in there ah think a whole twenty minutes, an he came back oot, "ah cannae handle that". Ah don't know if maybe he didnae just have the time tae write or if he never thought. Ah did, ah did say tae him afore he went in "there's a diary on her table eh just put some of your thoughts and feelings in it...if you want". But when he left ah checked it an he never put anything in. Ma grandpa's just no the very talkative type so ah think maybe he's just looked at it and thought 'nah you're alright', or maybe he's too old for that stuff. Ah don't know but aye ah thought it was good. (Katrina FM4)*

A nurse who had cared for this family gave an account of what she observed with regards to the male family members and their engagement with the diary.

*Ah don't think they wrote in the diary cause they didn't come intae see her very often. They didn't really, they didnae like it, they didnae like the unit and stuff like that so ah think that they only came in maybe aboot two or three times...an ah don't think they wrote in the diary. (Beth N4)*

Therefore, the way that male family members react to and cope with the situation they find themselves in appears to have an effect on their ability to write in the diary so may not necessarily be gender or age specific but dependent on the individual (*see 4.5.1 Emotional effort*).

Another factor associated with gender and writing ability was the area in Scotland where the ICU was situated.

*...ah think women are more inclined to be writers than men. Ah think especially in this, in this kind of area, ah don't know what it's like in (other areas) but ah can only speak for here.*

*The older men, it's physically cause they are not good at writing "oh ah was never good at writing at school". Writing is something that they don't tend to do on a day to day basis unless they've got the type of job*



*but a lot of kinda manual workers don't sit down and write. Ah think that's got a big thing tae do with it. An older men especially when they left school, when a lot of them were like fourteen, fifteen an they maybe write their name on a Christmas card or whatever but their wives do all the rest of the writing...d'you know a lot of them just don't. (Fiona N5)*

The level of literacy, in the area covered by the ICU, was a concern for nurses and had to be considered when encouraging family members, male or female, to write in the diary.

*Ah think that's why it's important at the very beginning to say "we don't correct your spelling d'you know we're no looking tae see you know how you write or what you write we just want you to write something that's important, or a message that you maybe want to pass on"(Fiona N5)*

However, nurses were sometimes taken aback by the way some family members wrote in the diary, as one nurse explains.

*We had a woman. Her daughter just wrote down how she spoke, cursing an swearing. D'you know an that was just how it was. Am like that "Oh dear!" An then her, her mother was just laughing when she got better an saw it. (Jane N1)*

Therefore, it is difficult to separate gender from other factors such as age and literacy, which may also have an impact on how the diary is used. Nevertheless, it was through exploring the issue of male family members and diary use with participants that age and literacy were raised by participants.

#### **4.7.1 Summary**

In summary, the theme gender, arising from the issue of male family members and diary use, has been portrayed mainly by female participants. However, one male nurse and one male patient who had previously been a family member in ICU gave further insight. It was reported by nurses and family members that male family members were less likely to write in a diary in ICU than female family members were. An example of a male family member using a diary in ICU suggested that there are similarities between how male family members and female family members use diaries, apart from not using the diary for emotional support. When it came to discussing male family members and diary use, participants spoke about other factors



including age and ability to write. However, ability to write was also discussed in relation to how the individual family member was coping with the situation and the level of literacy in the area where the ICU was situated.

## 4.8 Chapter Summary

This chapter has provided an in-depth overview of key findings from the PhD study ‘Critical Care Diaries: a qualitative study exploring the experiences and perspectives of patients, family members and nurses’. The five main themes of information, communication, emotion, person centered and gender have been discussed in detail and summarised, including sub themes associated with these.

Diaries were found to support information sharing with patients and family members, having been created and co-authored by nurses and family members in the ICU for patients to read during their recovery. Through the process of sharing information, nurses and family members communicated with the patient. Diaries contained information about what happened when the patient was in ICU and were written with the knowledge that the patient would read this. However, information contained in the diary was read by nurses and family members throughout the ICU stay whereas patients mostly read this after being in ICU and thus information was interpreted differently by the different groups. Presence was established for individuals involved directly and indirectly in the patient’s experience of critical illness and as information written in the diary represented time in which the patient was not there, the diary represented the patient and thus established the patient’s presence in ICU.

The diary was experienced as helpful in facilitating and enhancing communication between nurses, family members and patients during and after the time in ICU. Family members experienced writing in the diary as a way to communicate with their loved one when there was no other way, whereas nurses referred to the diary to help initiate and guide conversations with patients and family members. Patients referred to the diary after the time in ICU and found this helpful when speaking to others about their experiences. However, some patients also reported writing in the diary to acknowledge others and document how they were getting on with their recovery. Furthermore, the presence of the diary encouraged other aspects of communication

for example the unspoken word, with family members writing thoughts and feelings in the diary that they were unable to say out loud.

Emotional support was experienced by family members from writing in and reading the diary during the time in ICU whereas patients experienced emotional support from reading diary entries after ICU. However emotional effort was associated with reading and writing in the diary during and after the time in ICU for family members, patients and nurses. The emotional effort experienced was different between groups and individuals. For example, nurses sometimes found it upsetting reading what family members had written whereas there were reports of some family members being unable to write in the diary and for patients reading the diary for the first time was an emotional experience.

The diary was experienced as an integral part of the care provided by nurses in the ICU to the extent that some patients and family members took this for granted. However, patients and family members appreciated the effort nurses made to write in the diary, recognising that they did this without knowing the patient and their family and were busy. Whereas, nurses gained an insight from reading the diary and got to know the patient and their family better. Patients and family members were comforted through knowing who looked after them and therefore the identity of those who wrote in the diary as well as those who the diary was written for or about was present in the diary.

Finally, male family members were found to be less likely to write in the diary compared to female family members with factors such as gender and literacy being highlighted as potentially influencing interaction or engagement with the diary. However, this was reported mainly from a female perspective. Reporting on multiple experiences and perspectives demonstrated the different ways in which diaries are used and experienced during and after the time in ICU. To conclude, although the diary is primarily written for the patient, family members, nurses and patients use the diary in different ways to support their needs and others needs throughout the experience of critical illness.



## Chapter 5 Discussion

### 5.1 Introduction

The overall aim of this study is to gain an understanding of the perspectives and experiences from patients, nurses and family members in relation to using diaries throughout the critical illness journey. The main research questions are:

1. What is the patient experience of having a diary?
2. What is the nurse experience of using a diary?
3. What are family member experiences of using a diary?

This chapter aims to explore and make sense of the findings presented in the previous chapter. The different experiences and perspectives associated with using diaries from patients, nurses and family members are interconnected. Therefore, the discussion will be structured using emergent themes from the data analysis rather than by group. These are information, presence and communication, emotion, person centered and gender. However key findings specific to each group will be highlighted and discussed using relevant literature, including findings from research on diaries. In this way, the research questions are addressed and findings discussed in relation to them.

The complexity of what a critical care diary is and what it means or how it is experienced by people at different times is evident in the reported findings. The concept of ‘Stories as joint actions’ will be used to frame and support discussion of the findings.

‘Stories as joint actions’ was introduced by the sociologist Ken Plummer in chapter 2 of his book *Telling Sexual Stories: power, change and social worlds* (Plummer, 1995), see Figure 24. Following on from an earlier version of the model presented in the literature review chapter and concerned with life story actions (Plummer, 1990), both are influenced by Symbolic Interactionism. Plummer expressed an interest in helping to develop a sociology of stories which for him was concerned with the ‘social role’ of stories rather than the ‘formal structure’, for example how stories are

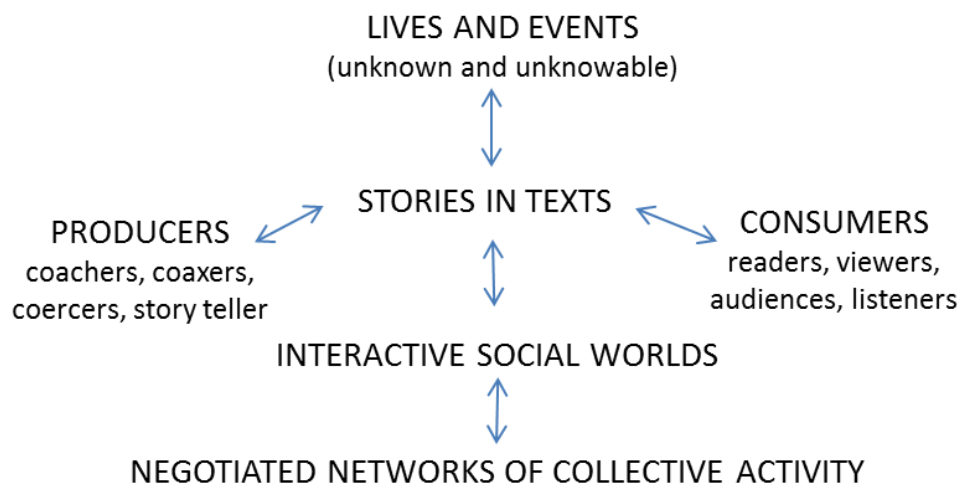
produced and read or how they change and the role they have in different contexts or ‘the political process’ (Plummer, 1995). In the opening discussion of chapter 2 entitled *An invitation to a sociology of stories*, Plummer states that his ideas

*“...could be applied to any story telling process: the focus on sexuality is merely one instance.” (Plummer, 1995, p. 19).*

With regards to critical care diaries the concept of stories as joint actions acknowledges the contribution of different individuals or ‘producers’ in creating the diary as well as those who read the diary, ‘consumers’. The diary is essentially a story of what happened when the patient was in ICU, written to and for the patient from the shared perspectives of nurses and family members. Plummer states:

*“Stories get told and read in different ways in different contexts.” (Plummer, 1995, p. 22).*

Therefore ‘Stories as joint actions’ provides a useful model to explore and understand the experiences of diaries from multiple perspectives by acknowledging joint actions occurring with and around the diary throughout different stages of the critical illness journey.



*Figure 24: Stories as joint actions (Plummer, 1995, p. 23)*

Each theme highlighted in this introduction will be discussed and aspects of Plummer's model 'Stories as joint actions' will be explored in relation to each theme and the multiple experiences and perspectives of critical care diaries. Additionally, more recent work by Plummer (2013) on social stories, *A manifesto for Social Stories*, will be referred to.

## 5.2 Information

*"Just how a story is crafted depends on many changing events resting on a fivefold structure of when it is being told (time), where it is being told (place and space), who is being told (audience), why it is being told (motivation), and what is being told (contents)." (Plummer, 2013, p. 212)*

The diary as a story is created or crafted during the time in ICU by nurses and family members. It is written to and for the patient in response to a critical illness event and handed over to the patient for them to read and refer to during their recovery. In this study participants often referred to 'what is being told' or in other words the information contained in the diary. Nurses appeared to be concerned mainly with how information was presented in the diary whereas family members and patients spoke more about what this information meant to them and how they used it.

Nurses were responsible for starting the diary and wrote the 'first' entry, explaining the reason for admission to the ICU and what had been happening. This is widely accepted practice having first been reported in an early diary study by Bäckman and Walther (2001) who advised that the diary should begin with a summary including

*"...the reason for admission, the initial events in the ICU and the current state of illness" (p. 427).*

Nurses continued to write in the diary during the time the patient was in ICU and encouraged family members to participate. Therefore, diaries in this setting were often co-created by nurses and family members who were producers of the diary, whereas patients were consumers.

All participants interviewed in the current study were involved in using diaries with entries from both nurses and family members. In the UK, this appears to be the

preferred method for authoring the diary, with the invitation extending to other healthcare professionals involved in the patient's care (Combe, 2005; Robson, 2008; Jones, 2009; Hale, 2010). This did not routinely happen in the ICU where the study took place. However, during an informal conversation with one of the medical staff, the researcher learned about an entry written in a patient's diary following a significant event (medical procedure). Participation from family members extended beyond the ICU with nurses encouraging and welcoming contributions from those unable to visit the patient. Drawings and letters from children were placed in the diary for safe keeping, reported in other ICUs (Combe, 2005; Gjengedal, et al., 2010) and an approach used by Ewens et al (2014) where family members, including children, were encouraged to write or draw entries in the diary in ICU.

Research focusing specifically on the content of diaries has included diaries with photographs of the patient, for example Åkerman et al (2013). However, studies by Roulin et al (2007) and Egerod and Christensen (2009), exploring the content and structure of diaries in ICUs where photographs were used, have based their analysis on the written content of the diary only and the findings are therefore useful in comparing the content and presentation of information in the diaries used in the current study, which do not contain photographs.

In this study, a difference between the content of information written by nurses and family members was reported yet information written in the diary from both groups was referred to as 'day to day' information. Roulin et al (2007) found entries in the diaries they analysed contained explanations and descriptions of daily events and stories, written to the patient from the perspectives of healthcare professionals who were mostly nurses and family members. This information formed the main part of the diary and was described as 'Sharing the Story', one of four themes discovered in the main category 'Sharing throughout the ICU time'. Stories about the illness and treatment, events taking place at home, what the patient was doing, for example the activities they were involved in and their behaviour, was shared by family members with nurses and recorded in the diary. Therefore, the content of day to day information or stories written by nurses and family members may appear quite different. However, Roulin et al (2007) acknowledge this information is shared in

the diary, contributing towards a bigger story representing the patient's time in ICU and what was happening during this time.

In addition to day to day information and 'Sharing the Story', Roulin et al (2007) introduced the themes 'Sharing the Presence', 'Sharing Feelings' and 'Sharing through Support' to illustrate the various aspects of sharing, similar to that reported in this study between nurses and family members. For example, family members wrote about what they were thinking and feeling, 'Sharing Feelings', as well as what was going on at home, 'Sharing the Story'. Reading about family members' thoughts and feelings in the diary gave patients an insight into what their family had experienced, a finding reported by others (Engström, et al., 2008; Robson, 2008).

In contrast and in keeping with what Roulin et al (2007) describe, nurses in this study focused more on writing about what they observed in the ICU with the patient. Information about the patient's progress, how they were responding, significant events and descriptions of nursing care, including environmental factors and sensory experiences that the patient may be able to relate to later on were recorded, 'Sharing the Story'. Additionally, contact and visits from family members or friends and a summary of conversations with the family and patient, whether they were able to respond or not were documented similar to 'Sharing the Presence'. Therefore, as seen in Plummer's model of Stories as joint actions, what was going on in the 'Interactive Social World' of the ICU fed into the content of the diary.

Findings of this study indicate that learning about the diary, how to use it and what information to write, came mostly from nursing staff in the ICU who encouraged family members to participate. Nurses as producers of the diary therefore had two roles, identified by Plummer (1995) in the following quote.

*"Closely allied to these tellers are a second kind of producer: the coaxers, coaches and coercers. These folk possess the power at least momentarily, to provoke stories from people." (p. 21)*

Nurses are story tellers and in addition coaches and coaxers, guiding the story by advising family members and each other what to write about (coaching) as well as encouraging people to write and tell stories in the diary (coaxing).



*“...just write messages for your relative that they would like to read when they improve and when they get better...” (Jim N6)*

There were no reports however from any patients or family members of nurses as coercers in relation to the diary. From spending time in the unit and speaking to staff informally it became apparent that writing in the diary was a voluntary activity for nurses and family members, people did not have to write in the diary if they did not want to. Likewise, patients were given a choice if they wanted to receive their diary or not and even after accepting the diary it was up to the patient if and when they wanted to read their diary, witnessed during a small number of observations with nurses handing over diaries to patients.

Information, although written to and for the patient, was read by family members who reported often knowing about this prior to reading it in the diary, having already been updated by the nurse at the bedside. However, one family member found unexpected information in the diary regarding a change in her husband's condition which although had resolved by the time she visited made her feel worried. Ewans et al (2014) found similar accounts from interviewing patients post ICU who reported that sometimes family members were scared about their loved one's well-being and prognosis after reading entries written by staff in the diary. Therefore, family members are not just producers of the diary but also consumers, making it important for nurses to consider the effect information may have on family members as well as patients.

Less commonly reported is the participation of patients in diary writing, yet two out of the four patients interviewed had written at least one entry in their diary before being discharged home. Information about stepping down from ICU level care, feelings towards family members and staff, and comments about progress e.g. physical and psychological functioning were described in diary entry examples from patients in this study. Continuing the diary after ICU has been reported in other studies with patients, family members and staff writing entries (Bäckman & Walther, 2001). Originally suggested and asked for by patients (Bäckman & Walther, 2001; Robson, 2008), this approach has been reported in a qualitative study looking at ICU survivors' use of diaries post discharge (Ewens, et al., 2014) and an ICU diary

program introduced in a military hospital (Locke, et al., 2016). Ewens et al (2014) found that a small number of participants wrote in their diaries after ICU to respond to what the nurses had written and to fill in gaps. Ewens et al (2014) went on to report that this activity generated ‘mixed emotions’ for patients as they were exposed to what had already been written in the diary during their time in ICU.

Knowing that the patient would read the diary at a later date influenced how the story or diary was crafted and therefore the way in which information was presented. Nurses were particularly aware of this, referring to the type of language they used and how they structured diary entries written for the patient. They tried to write in a way that patients would understand, reflecting recommendations from the diary literature that information presented in the diary is clear and written in a way that is easy for the patient to understand, using everyday language and avoiding the use of medical jargon or technical terms (Bäckman & Walther, 2001; Åkerman, et al., 2010; Egerod, et al., 2011a). Family members appreciated nurses writing in this way as they were able to read and understand the information and believed that their loved one would understand this too.

Structuring diary entries helped nurses think about what to write. The structure and content of nursing diary entries reported in this study, as mentioned earlier, are comparable with findings from a narrative analysis of diaries belonging to ICU survivors in Denmark where findings were reported at different levels of analysis, including at the level of diary entry (Egerod & Christensen, 2009). The authors found that each nursing entry started with a ‘greeting’ to the patient and ended with a ‘sign off’ note where encouragement was given, for example in the form of well-wishes. The main body of the entry contained the status of the nurse (narrator), patient and family as well as contextual cues. Nurses in the current study, in addition to structuring the content of the nursing entry, spoke about trying to personalise diary entries. However due to similar events experienced by patients in ICU, for example weaning from the ventilator, they found themselves writing the ‘same things’. Likewise, Egerod and Christensen (2009) found similarities with the characteristics of the diaries they analysed stating that:

*“...the illness trajectories unfold and become familiar. Patterns become similar as the plots converge towards variations of the restitution narrative.” (p. 271)*

The restitution narrative, a type of illness narrative introduced by Arthur Frank, contains information from before, during and after the illness with a focus on becoming healthy again (Frank, 2013). Egerod and Christensen (2009) suggest that the restitution narrative is the most common structure of narrative plot found in the diary with the nurse, patient and family taking centre stage. However, the diaries, like the ones in the current study, were from ICU survivors thus accounting for the dominance of the restitution narrative (Egerod & Christensen, 2009) and although written only by nurses, the content and structure of nursing entries were similar to that described by participants in this study.

Deciding what information to include and how to present this was raised by nurses and family members. Nurses spoke about writing what they thought would be of value to the patient, whereas family members spoke about writing what they wanted their loved one to read. Guidelines and instructions for authoring the diary can be found in many existing studies on diaries however it has been highlighted by Neilsen and Angel (2015b) in a systematic review of the literature that these are mostly targeted at staff. Furthermore, there is a need to develop guidelines and standards for diaries so that patients can use the diary to construct a coherent story from the time in ICU (Åkerman, et al., 2013). However, in areas where the diary is co-authored by nurses and family members it is important that instructions for family members are included and staff continue to encourage family members to participate.

Furthermore, consideration should be given to patients and their preferred diary content as there is a distinct lack of knowledge around what information patients want to see and read in their diary (Åkerman, et al., 2013).

Storli et al (2003) believe that patients should be able to ‘find recognition’ in their diary, achieved by using photographs, thoughts and descriptions of what has been observed as this will

*“...contribute to completing the patient’s own experience and make it more comprehensible” (p. 105).*

Aitken et al (2013) argue that there is currently a lack of empirical evidence and underpinning theory informing the content of diaries which needs to be addressed. However, as discussed, the diary is created out of joint or shared actions in the ICU between nurses and family members in relation to individual patients, which informs and influences the content of each diary. Therefore, making it difficult to determine the content of the diary as every diary is different and personal to each patient.

Information in the diary represented a version of reality based on what nurses and family members wanted the patient to read. Plummer (2013) states that

*“Stories are always a version of reality; and the presence of stories must always pose questions about their relationship to truth, fiction, reality, copying.” (p. 212)*

At the time of writing the diary patients are unable to give feedback or communicate how much and what information they want or need. Patients in this study generally looked for more detail in their diaries, which has also been raised in a previous study by patients as an issue with diaries (Egerod & Bagger, 2010). One patient who read that he had been anxious would have liked more detail about this episode.

*“...they (the nurses) said you know ah was ‘anxious last night’. What did they do or what was ah doing? How do they express anxiety?”  
(Graham P6)*

Without any further detail the information written about being anxious was meaningless to this patient when he read it. Where the content was lacking, beliefs such as the nurses not having enough time were seen as a contributing factor and patients found out from members of their family additional information missing from the diary, as reported in the findings chapter section 4.3.2 Presentation of information.

It has been recognised that keeping a diary adds to the ICU workload (Åkerman, et al., 2010) and the quality of the diary may be influenced by this (Robson, 2008). In a study evaluating the time taken by nurses to write diary entries it was reported that this activity took considerably less time than other nursing tasks, with each entry after the initial ‘first entry’ taking on average less than 6 minutes to write (Nydahl, et

al., 2014). However, the authors acknowledge that there was potential for bias with participants self-reporting the time they took to write each entry.

While there were reports of patients looking for more detail in their diaries there was one patient in particular who found the level of detail written by nurses in his diary frightening.

*“...some of the nurses had wrote that ‘you’ve got in tubes’ and things...that’s scary stuff to be quite honest with you.” (Steven P2)*

The way that participants interpreted information in the diary influenced the value they placed on the diary and how it was subsequently used. For example, the patient referred to above avoided reading certain information written in his diary. Writing information in the diary was viewed by nurses and family members as a way to make memories for the patient, thus influencing how the diary or story is created (Plummer, 2013). The diary was often referred to as a ‘memory book’ for patients, containing information that would have otherwise been lost or forgotten such as conversations that had taken place, things that had been said to the patient, events involving the patient, and what the family were thinking and feeling at that time.

Plummer (2013) acknowledges a link between stories and memories stating that

*“Our stories become our memories, giving shape to our lives.” (p. 211)*

It has been suggested by Williams (2009) that constructing a story may help patients with their psychological recovery from critical illness however the experience of being in ICU, especially when the admission is unexpected, can provide particular challenges for patients in being able to construct their story. Williams (2009) identifies physical weakness, neuropsychological deficits, unconsciousness, powerful emotions and feelings (which may have never previously been experienced) as a collection of factors which can

*“...overwhelm an individual’s cognitive/ emotional regulatory systems, resulting in numbness and shock.” (p. 285)*

Recent research by Stayt et al (2016), reporting on ICU patients' phenomenological accounts of story construction, found that constructing a story to make sense of experiences in ICU was an important need for patients and a process which occurred early on in their recovery. Williams (2009) and Stayt et al (2016) refer to diaries as one method that can facilitate patients with story construction. However, they recognise that patients are likely to require support from health care professionals in 'overcoming obstacles' (Williams, 2009) and 'early support' from health care professionals is important in facilitating story construction (Stayt, et al., 2016). Furthermore, Stayt et al (2016) found that families play an important role in supporting patients through this process and consideration should be given to how best to support family members so that they can support the patient.

Plummer (2013) notes that

*"...stories ground us in everyday life, often providing us with coherence and meaning." (p. 211)*

Patients in this study reported using information written in the diary to 'fill in gaps' they had from being critically ill in ICU. Filling in the gaps is one aspect of making sense of experiences and constructing a story (Stayt, et al., 2016), reported from patients in this study and others (Egerod & Bagger, 2010; Egerod, et al., 2011b; Åkerman, et al., 2013; Ewens, et al., 2014; Glimelius Petersson, et al., 2015). For example, patients in this study learnt about what had happened whilst realising how unwell they had been and what their family had been through, consistent with findings from previous research on patients' experiences of diaries (Engström, et al., 2008). Therefore, it is not surprising that diaries have been described as

*"...a source of information for patients, who needed to piece together their story at a later time." (Egerod, et al., 2011a, p. 236).*

Patients, family members and nurses shared the view that information contained in the diary was helpful to patients in this way and referred to this process as putting together a 'jigsaw' puzzle. Information in the diary was viewed as part of the jigsaw, an aid to putting the jigsaw together or both.

Additionally, family members used the diary to solve their own ‘jigsaw’ puzzle, however this was during the time in ICU. For family members, putting together the jigsaw puzzle was about trying to understand and remember what was going on with their loved one when they were still in ICU. Reading information written in the diary from nursing staff allowed family members to look back and make sense of what was going on, or as described by one family member

*“...get the clarification in your own mind...” (Angela FM1).*

Family members were actively reading information contained in the diary for their own information needs, as they reported finding it difficult to take in all the information they were told each time they visited. Garrouste-Orgeas et al (2014) found that family members used the diary to access and understand medical information about the patient which they then shared with other family members. The main features of the diary which supported this were information being written in everyday language, a finding reported by Johansson et al (2015), and the opportunity for family members to re-visit this information as often as they wanted. Neilson and Angel (2015a) reported family members being able to keep track of time and monitor the progress of the patient, which was an important finding for family members in this study too. Family members in this study spoke about how the diary helped them see the progress their loved one was making and actively looked to the diary for evidence of ongoing progress. They used the information to put things into perspective over a longer period of time thus reviewing where things had started for their loved one and where they were now. Neilson and Angel (2015a) found that

*“...writing and reading the diary allowed relatives to incorporate an understanding of the critical situation into their self-understanding.” (p. 5)*

Furthermore, information in the diary was interpreted as a progression of the patient’s journey through the critical illness, a journey described by patients as a progression from being critically ill to getting better and waking up. Reading information in the diary gave patients and family members an opportunity to reflect on different aspects of the critical illness experience at different times throughout the journey.

In summary, the diary was co-created by nurses and family members who were the main producers of the diary in ICU, including family members who were unable to visit at this time. The diary was written to and for the patient yet it was found that occasionally patients wrote in the diary during their recovery in the hospital and at home which is not commonly reported. There were differences in the content of day to day information written by family members and nurses however, this was comparable to findings from diary research focusing on the content of diaries (Roulin, et al., 2007). Nurses as the main producers of the diary, in the context of Plummer's (1995) model, were found to take on the roles of coacher and coxer by encouraging, advising and guiding others. Nevertheless, writing in the diary was a voluntary activity for both nurses and family members.

Knowing that the patient was likely to read the diary at a later date had an impact on how the diary or 'stories in texts' were created. Therefore, presentation of information in the diary in terms of the language used, the structure and decisions about what to write were taken into consideration by producers of the diary. It became apparent in diaries of ICU survivors that Frank's (2013) 'restitution narrative' was the most common structure of narrative plot (Egerod & Christensen, 2009). However, the narrative or story contained in the diary was a version of reality constructed from the perspectives of nurses and family members during the time in ICU which meant that patients did not always get the information they wanted or needed during their recovery. Interestingly patients believed a lack of detail in their diary was related to nurses not having enough time to write rather than decisions being made about what information would be of value to the patient.

Finally, the way that participants interpreted information in the diary influenced how the diary was valued and used. Patients and family members turned to the diary to fill in gaps otherwise described as putting together a jigsaw puzzle. The value of patients constructing a story after a stay in ICU was discussed and the diary identified as a source of information for patients to begin to construct their own story. Whereas family members in addition to their role as producers became consumers of the diary, actively using it for their own information needs during the time in ICU which was a significant finding in this research.



### 5.3 Presence

The diary gave presence to patients, family members and nurses throughout the critical illness journey. Writing in the diary established and maintained the presence of the patient throughout the time in ICU and acknowledged the presence of significant others, who were involved with the patient during this time and thus part of the story of what happened in the ICU.

Patients referred to the diary as

*“...a record of when you weren’t there...” (John P1)*

Therefore, acknowledging their lack of presence during this time. The diary gave presence to the patient when they were in ICU and unable to determine or assert their own presence. Roulin et al (2007) found that presence was one aspect of sharing throughout the time in ICU, other themes have been discussed already in the information section. ‘Sharing the Presence’ related to the continual presence of someone at the patient’s bedside, ‘The Presence of the Writers’, as well as ‘The Presence of the Patient’. The presence of the patient was maintained in ICU through writing to them on a regular basis, a finding reported in the current study.

Establishing and maintaining the patient’s presence was particularly important for family members as they struggled with their loved one’s lack of presence during this time

*“You’re limited to what you can say...she was sedated, she wasn’t with it...” (Lynn FM3).*

As found in this study and by Roulin et al, the diary

*“...created a link to the person beyond the ICU patient and a way to preserve personhood.” (Roulin, et al., 2007, p. 897)*

Thus, not only giving presence to the patient, but giving presence to the patient as a person in ICU.

One role performed by family members in the ICU is an ‘Active Presence’ at the patient’s bedside, whereby family members are physically and actively present and

wish to maintain a vigil (McAdam, et al., 2008). Being able to perform this role is not just important for family members but also for patients in ICU who feel safe when they experience the presence of family members (Hupcey, 2000; Olsen, et al., 2009). In the ICU where the study was conducted, restricted visiting times meant that family members were only allowed to visit for one hour in the afternoon and one hour in the evening. When family members were able to visit, they did not know if their loved one would know they had been there with them, confirmed by patients who had little insight into who had been with them until reading their diary.

*“...ah maybe didn’t even remember them being there but because they’d written it am like that ‘oh aye you were in’.” (Alison P4).*

Diary entries dated and signed by family members provide evidence that the family has been physically and actively present at the patient’s bedside, a finding recognised by others (Roulin, et al., 2007; Garrouste-Orgeas, et al., 2014). Furthermore, recent studies exploring the experiences and perceptions of family members writing diaries have reported that writing creates a feeling of ‘togetherness’ between family members and the patient (Nielsen & Angel, 2015a) and between family members and nursing staff in the ICU (Johansson, et al., 2015). Whereas for patients, finding confirmation in the diary that family members visited is of great value to patients as well as reading the entries that family members write (Engström, et al., 2008). Patients in this study realised they were not alone when they read the diary

*“...they went through it with me, not physically but they went mentally through it.” (John P1).*

It has been found that although documenting visits in the diary may be beneficial for the patient it can cause feelings of guilt and stress for family members if they have been unable to visit or do not know what to write in the diary (Johansson, et al., 2015). In the current study, it was found that people did not need to write in the diary or even be present in the ICU to have their presence acknowledged with the patient. Presence was witnessed and recorded by the main producers of the diary who wrote about and included those able and unable to visit the patient in ICU.

Nurses wanted to reassure patients they were not alone and someone was with them all the time. One nurse reported writing comments in diaries such as *'we're all here'* or *'the nurse is with you all the time and your family have been in'* (Valerie N3).

Egerod and Christensen (2009) have shown that diaries written by nurses record the continual presence of the nurse with the patient in ICU along with the status of the patient and their family. Whilst reassuring the patient they had not been alone, family members were reassured too when they visited and both patients and family members were informed of what had been happening when they were 'not there'. In this way, the diary provides the patient and family with evidence of the nurse(s) being physically present with the patient in ICU whilst also describing different aspects of nursing care and other treatments performed with the patient in ICU. Therefore, presence is one of several stories, 'stories in texts' (Plummer, 1995), jointly created and co-existing in the diary and individual diary entries.

Snyder et al (2000) provide an overview of presence as an intervention in nursing and discuss the use of presence in critical care nursing as a simple way to transform

*"...a technical, potentially impersonal setting into a humane, healing place." (p. 27).*

Presence can be used separately or in combination with other interventions and procedures in the ICU setting. The technique of 'centering', where the nurse focuses their attention on the patient before proceeding with any caring activity is discussed as well as dedicating a few minutes to the patient without attending to the wide array of equipment often in use (Snyder, et al., 2000). Therefore, it could be argued that taking time to write diary entries to patients in ICU allows and enables nurses to focus on and be present with the patient as a person in ICU.

Plummer (2013) states that

*"Stories help keep us alive: that is their work." (p. 211).*

In the ICU, it would appear that the diary helped to keep the patient alive by acknowledging and giving them presence during this time. Writing in the diary situated family members, friends, nurses and other healthcare professionals with the

patient in ICU, including healthcare staff from other areas and family members who were unable to visit. Using Plummer's (1995) model, the ICU represents an 'interactive social world' in which the patient, their family members and others outside the ICU are temporarily part of while the patient is critically ill. Therefore, the world of ICU, through the diary, becomes entangled with other interactive social worlds relating to the patient and 'negotiated networks of collective activity' such as the patient's family.

In summary, the diary gave presence to the patient when they were in ICU and unable to determine or assert their own presence, as a result of the critical illness and need for supportive treatment. This was especially important for family members who found it difficult visiting a loved one in ICU who did not respond. Through writing in the diary family members and nurses were able to establish and maintain the patient's presence, their own presence and the presence of significant others. Patients realised they had not been alone, family members were reassured someone was always with their loved one and nurses' constant presence with the patient was documented. When the diary was used, the patient was valued as a person in the technological world of ICU. Presence was shared between producers of the diary who wrote about themselves, the patient and those people who were important to the patient or encountered the patient in ICU, as well as consumers of the diary.

## **5.4 Communication**

The diary was used in a number of ways by nurses, family members and patients to facilitate communication during and after the time in ICU. When the diary was being written in the ICU it opened up a channel for family members to communicate with their loved one. Nurses read and referred to the diary in ICU to assist communication interactions with family members and the patient. After ICU patients shared the diary with others to talk about their experience of critical illness. Therefore, the diary became more than the story of what happened to the patient as it supported communication between the patient, family members and nurses during and after the time in ICU.

Diaries are written for patients to read in the future however, family members in this study experienced writing in the diary as a way of talking or having a conversation with their loved one in ICU when there was no other way, a finding recently reported by Johansson et al (2015). Through establishing and maintaining the patient's presence in ICU the diary enabled family members to continue communicating with the patient,

*"...writing the diary helps me communicate to Graham when ah can't...it just opens up that, as if he was there, as if ah could talk to him." (Jean FM6).*

Furthermore, the diary offered those who were unable to visit a way to keep in contact,

*"...they don't let kids in but she can still communicate with her gran..." (Katrina FM4).*

Contributing to the diary ensured that the patient remained part of the family and as highlighted by Garrouste-Orgeas et al (2014)

*"...included within the family story, so that the structure of the family remained intact" (p. 8).*

This is reflected in the way family members reported writing in the diary, with the frequency of writing decreasing as the patient began to waken and eventually stopping when they were able to communicate, or as described by family members 'hold a conversation'. This finding was observed by Roulin et al (2007) in some of the diaries they analysed:

*"The diaries seemed to be a vehicle for maintaining communication with the patient while he or she is unconscious or confused. In some diaries, entries stopped as soon as the patient was well enough to talk and actively interact." (p. 897)*

Nurses reported continuing to write in the diary until the patient was transferred out of the ICU whereas Roulin et al (2007) did not distinguish any difference between family members and nurses writing in the diary. More recently it has been reported that changes in the patient's condition can affect the way in which family members

use the diary (Garrouste-Orgeas, et al., 2014) and as seen in this study family members were writing in the diary to communicate with the patient in ICU when there was no other way. Whereas nurses were writing in the diary to communicate with the patient in the future, during their recovery after ICU.

Family members communicated through the diary ‘The unspoken word’, a code used to describe the personal thoughts and feelings people (family members) wrote in the diary which would not normally be shared or said out loud to one another. As one family member explains

*“...sometimes you can say something in a text or letter that you wouldn’t necessarily verbally put out there...” (Angela FM1).*

The reality and experience of having a loved one in ICU who was critically ill and might not survive brought to the surface thoughts and feelings which were often too difficult or ‘painful’ to communicate verbally, however could be written down in words in the diary and kept. Therefore, the diary provided a channel for family members to communicate unspoken words as well as engage in everyday conversations with their loved one. Plummer states

*“Stories help people to say certain things at certain times and in certain places, and likewise not to say them at others.” (1995, p. 172)*

Recent studies exploring family members’ experiences with diaries have found that writing in the diary makes it easier for family members to express ‘difficult-to-say words’ or ‘previously unexpressed feelings’ by providing a way in which the family member can put their thoughts into words (Johansson, et al., 2015; Nielsen & Angel, 2015a). Through the diary the family member becomes engaged in

*“...an intimate inner dialogue with the patient” (Garrouste-Orgeas, et al., 2014, p. 5)*

When read by healthcare professionals this has been perceived as intruding into and violating patients’ and family members’ privacy in the ICU (Périer, et al., 2013). Nurses recognised and respected that family members communicated in this way through the diary and experienced reading such entries as ‘private’ and

‘confidential’. Whereas patients appreciated entries from family members and friends as it made them realise how much people cared whilst giving patients insight into what their family had been through, findings consistent with others (Robson, 2008; Ewens, et al., 2014) and reported by patients as bringing them closer together with family members.

Entries from family members have previously been highlighted as the

*“...most important parts of the diary...” (Engström, et al., 2008, p. 63)*

This was experienced and reported by patients who read entries from their family members detailing how much they loved them, which they accepted as they already knew this in their heart, however it had never been said to them before (Engström, et al., 2008). In this study, there was one example where a patient was quite upset and angry with diary entries written by two of her sons,

*“You know, it’s alright when they think their mother’s dying ‘oh mum’ but when she’s alright ‘get on with it...” (Alison P4).*

Therefore, finding ‘unspoken words’ communicated through the diary was not necessarily appreciated by the person it was written for especially if they did not believe or had never experienced such feelings from those writing unspoken words in the diary. Plummer (2013) in the opening paragraphs of ‘A Manifesto for Social Stories’ cautions that:

*“These stories have significance and we need always be mindful of the tales we tell and the tales we hear: stories have consequences. We should always be careful of the tales we tell, for stories and their documents are our futures. We should ask just how stories work their ways in human social life.” (p. 209)*

The consequences of stories will be revisited in the following section on Emotion in relation to the emotional effort and support experienced by family members, nurses and patients in association with writing in and reading the diary.

As discussed in the section on information, nurses were very aware of what and how they wrote to patients in the diary, knowing that the patient was likely to read this at

a later date. In terms of communicating with the patient through the diary nurses spoke about explaining procedures and daily events to the patient as they would have done if the patient were awake. However, in addition to this, nurses purposefully referred to information written in the diary, mainly from family members, to initiate and guide conversations with family members and patients during the time in ICU. Nurses referred to entries from family members to calm, reassure and re-orientate patients to their surroundings when the patient was beginning to waken,

*“...ah find it does kinda help people to get a bit less confused and maybe a bit less frightened when they're starting tae wake up.” (Beth N4).*

Furthermore, when nurses were having difficulty communicating with a family or wanted to find out how a family was coping and what their understanding of the situation was they would read recent entries written by family members to inform and enhance future interactions and communication with the family. Therefore, the diary helped nurses communicate with patients about what was happening as well as facilitating communication interactions with family members and patients in the ICU, which to the researcher's knowledge is an original finding. However as highlighted in the findings chapter this was dependent on family members writing and sharing information about themselves and their loved one in the diary.

During the time in ICU patients were often unable to read or write in the diary and therefore did not use the diary at this time as a way to communicate with others. Patients reported that the diary helped them talk to others about their critical illness experience after the time in ICU, referring to their diaries to re tell and communicate their story to different people.

*“It fills in those gaps. ...ah can refer back to this (the diary) ...and talk, talk them through it.” (Graham P6).*

Egerod et al (2011b) found that in the context of the illness trajectory it was important for post-ICU patients to be able to construct their illness narrative. Patients combined different sources of information including information in the diary which although incomplete acted as a 'pretext' and 'catalyst' for communication with others about their ICU experience (Egerod, et al., 2011b). The diary was shared



and read together with family members to talk through events, experiences and memories from the time in ICU, thus acting as a tool to open up discussions and communicate with family members and friends after ICU (Åkerman, et al., 2013; Glimelius Petersson, et al., 2015). However, using the diary as a tool for communication after ICU is dependent on whether patients want the diary, have access to the diary and whether they feel ready and able to read the diary.

In the context of the critical illness journey and when examined from multiple perspectives diaries are more than a document to record and communicate to the patient what happened when they were in ICU. Plummer's (1995) model can be incorporated to give further clarification. As highlighted, various communication interactions occur around writing and reading the diary, or in other words the social process of producing and consuming stories in texts. While jointly creating the diary, family members and nurses actively refer to stories in the diary and use the diary as an object to facilitate communication with each other and the patient during the time in ICU. Although aimed at the patient after ICU the diary opened up a live connection between 'producers' and 'consumers' of the diary in ICU. Furthermore, after ICU, patients shared information in the diary with others to facilitate communication relating to their critical illness experience. The diary became part of the patient's story or illness narrative, referred to by patients to explain to others what happened during the time in ICU. Therefore, patients who were originally consumers became producers, co-creating their own story through joint actions with the diary and with others who may or may not have been involved in producing the diary in the ICU.

In summary, the diary gave family members a way to communicate or talk with their loved one in the ICU when there was no other way and allowed them to communicate, through the diary, 'the unspoken word'. Nurses referred to information contained in the diary to initiate and guide conversations with patients and family members in the ICU which was particularly helpful when looking after patients who were beginning to waken up or to facilitate and support communication interactions with family members in the ICU. After the time in ICU patients found the diary helpful to talk through events with others and the diary acted as a tool for

communication by helping to initiate and open up conversations between patients and their family members. The diary became more than the story of what happened in the ICU as it facilitated communication interactions during and after the time in ICU between patients, family members and nurses. Therefore, people in the diary and the diary as an object came alive through the interactive process of communication during and after ICU.

## 5.5 Emotion

Two main areas of emotional experience, emotional effort and emotional support were associated with writing in and reading the diary. Emotional effort was experienced by family members and nurses co-authoring and reading the diary in ICU whereas patients experienced this from reading the diary as they recovered. Emotional support through writing in the diary was specific to family members however both family members and patients experienced emotional support from reading the diary. Emotional support, unlike emotional effort, was not reported by nurses in association with writing in or reading diaries.

Recent research on family members' experiences with diaries, including findings from this study, highlight the potential diaries have in supporting family members emotionally during the time in ICU (Garrouste-Orgeas, et al., 2014; Johansson, et al., 2015; Nielsen & Angel, 2015a). However less commonly reported is the emotional effort experienced by family members from reading and writing in the diary. Family members described the time in ICU as being on an 'emotional roller coaster' which appeared to have an effect on how they reacted to and experienced the diary,

*"...it's just how ah felt when ah read it whether ah wanted tae hit them (the nurses) or say 'thanks very much'..." (Katrina FM4).*

Roulin et al (2007), with regards to writing in the diary, noted from entries written by family members about their feelings that their 'state of mind' appeared to be dependent on the patient's condition.

*"When the patient's situation worsened they would feel low and when he was better there was joy: "Yesterday we were euphoric, today we are dejected." (p. 898)*

Families find themselves in a constant state of uncertainty when a member is admitted to ICU, causing profound suffering and vulnerability (Eggenberger & Nelms, 2007). From the initial hours and days to the following weeks, coping with the feeling of uncertainty is an ongoing challenge for family members of critically ill patients (Ågård & Harder, 2007). This can be exacerbated further by changes in the patients' condition or care in the ICU (Schmidt & Azoulay, 2012) which may account for fluctuations in the way some family members react to reading the diary in ICU.

In contrast, reading the diary supported family members through the experience of critical illness and although the diary was written for the patient to read later on, family members experienced an 'immediate effect' on their feelings in the ICU. One family member was able to see the progress her husband was making which helped her to cope while another said

*"...some days ah would go in there feeling really, really alone and read what one of the nurses wrote, an it totally lifted ma spirits." (Katrina FM4).*

Reading the diary gave family members a record of people's thoughts and good wishes as well as reassuring them that nurses cared and were doing everything they could which was comforting and created hope around the possibility of improvement in the patient's condition (Garrouste-Orgeas, et al., 2014; Johansson, et al., 2015),

*"...you take another thought and think 'no well he must be improving' you know they wouldnae write that if he wasnae..." (Heather FM2).*

A literature review concerning the needs and experiences of family members in ICU found that hope, reassurance and being in close proximity to the patient were important emotional needs of family members (Verhaeghe, et al., 2005) which can be met to some extent through interacting with the diary.

Family members experienced further emotional support from writing about thoughts and feelings and the physical act of writing. The diary gave family members an opportunity and a way to express and share their innermost thoughts and feelings, such as the 'unspoken word' discussed earlier, and to get their 'emotions out',

*“...for me its therapy...to get your emotions out” (Angela FM1).*

Experiences of doing this were described by family members as ‘getting it off your chest’ and ‘feeling like a weight had been lifted’ which for some family members helped to stabilise their mood when visiting and prepared them for future visits. Garrouste-Orgeas et al (2014) found that diary writing promoted ‘better emotional regulation’ for family members as they were able to express ‘strong’ emotions in the diary which created distance from those emotions and helped family members maintain hope. Similarly, Nielson et al (2015a) found that in addition to the ‘unloading of emotions’ and ‘expression of feelings’, creating the diary was a ‘meaningful activity’ where personal space for reflection and distance from events allowed understanding.

The act of writing gave family members something to do, involved them in care and shifted their focus to the future which helped them cope with the situation and acted as a distraction. However as observed by nurses not all family members needed or wanted to use the diary in this way. Furthermore, the need and importance of the diary in providing emotional support to family members became less as the patient began to recover, a finding also seen in this study with family members writing in the diary to facilitate communication with the patient during the time in ICU.

Although family members received emotional support from writing in the diary, participants in all three groups spoke about family members who were unable to write in the diary,

*“She said ‘just you do it mum’ she was too upset to do anything...”  
(Heather FM2),*

Thus, highlighting that some family members are more able to write in a diary during this time than others. Furthermore, Johansson et al (2015) have reported some negative effects of diary keeping for family members in ICU, for example those who do not know what to write can experience feelings of stress, guilt and failure. The family members interviewed in this study did not report any negative effects on themselves from diary writing however as highlighted emotional effort was

experienced by family members with reading and writing in the diary during the time in ICU which is an area requiring further research.

Reading the diary was described by patients as an ‘emotional experience’, especially the first time reading the diary which was often upsetting for patients as found by others (Robson, 2008; Egerod, et al., 2011b). Similarly, Engström et al (2008) reported the initial reading was

*“...filled with strong feelings and reactions” (p. 63)*

and it could be difficult for patients to continue reading once they started. This was reported by patients in the current study as demonstrated in the following quote,

*“...ah read the first page. The tears were in ma eyes and ah just shut it and put it back...it was two or three days before ah went back to it...it hits the heart strings.” (John P1).*

The diary contains a story of the patient’s struggle to survive which can be threatening and provoke strong emotions, ‘To encounter the menacing’ as described by Storli and Lind (2009) from the interpretation of patients’ experiences with diaries as part of a follow up service. Reading about what happened combined with what family members had been thinking and feeling during the time in ICU was quite a shock for patients in this study and aroused mixed emotions, which were both positive and negative (Robson, 2008; Engström, et al., 2008; Åkerman, et al., 2013; Ewens, et al., 2014).

*“...ah had smiles and tears. Sad tears, happy tears...shock as well.” (Alison P4).*

Furthermore, some patients experienced a feeling of guilt in response to what their family had been through and blamed themselves for what happened,

*“...that was devastating...ma mind just kept birling...’what have ah done?’, ‘what have ah put them (my family) through?’ ...ah had no idea.” (Alison P4).*

Other patients spoke about building up to reading the diary and making sure they were ‘mentally ready’ before reading it which could take some time and even in the

small group of patients interviewed this was very different for each individual.

Despite the multitude of emotions experienced and effort required to read the diary patients viewed the diary as positive and an important support during their recovery as reported by others (Engström, et al., 2008; Ewens, et al., 2014).

All patients experienced emotional support from reading the diary during recovery. Knowing what happened, who had looked after them and who had visited or phoned when they were in ICU was reassuring,

*“...it eased any anxieties ah had cause ah was quite anxious when ah came back (home), cause ah wasn’t sure what actually went on initially.”  
(Graham P6).*

The diary was personal to the patient and let them know how much people cared which was comforting to read, also reported by Glimelius Petersson et al (2015). Being able to read and refer to the diary kept patients ‘going’ and gave them ‘a wee boost’ as described by one patient who frequently referred to comments in his diary after ICU. However, the same patient was frightened and upset by certain information written by nurses which he deliberately blocked out when he read the diary. Therefore, it is possible that emotional effort and emotional support can occur simultaneously when reading the diary. Glimelius Petersson et al (2015) identified two patients in their study who chose not to read their diary and it was suggested that this

*“...may indicate avoidance behaviour and/ or a strategy for recovery.”  
(p. 7)*

In contrast, nurses did not experience any emotional support from interacting with the diary in ICU, although it has been suggested that writing the diary may be ‘cathartic’ for nurses as it is a way of demonstrating the care they provide in ICU (Phillips, 2011). Whereas emotional effort was sometimes experienced from reading and writing in the diary during this time. Writing about certain events, knowing that the patient would read this later on and reading entries from family members had an effect on how nurses felt. One nurse found it particularly upsetting to read entries from younger family members,

*“...if they’re writing to their dad that can be really quite upsetting for us...you can actually pick out the despair...that they just want their dad back and better, or their mum...” (Jim N6).*

Reading diary entries from family members made the situation ‘real’ for nurses and reinforced that the person they were looking after belonged to someone. While this was viewed as ‘not a bad thing’ it was acknowledged that if too much time was spent thinking about the real situation then they would be unable to do their job properly as they would be too upset. While there has been no previous research focussing specifically on nurses’ experiences of diaries, similar findings have been reported by Périer et al (2013) who examined a variety of healthcare staff’s perceptions on diaries, including nurses which highlighted the

*“...tension between being close to the families to support them better and maintaining the emotional distance needed to ensure optimal professional performance.” (Périer, et al., 2013, p. 5)*

Périer et al (2013) found that staff felt closer to patients and families when they read the diaries. Furthermore, writing about ‘negative events and bad news’ was a concern for ICU staff as not only did they have to deal with feelings of having failed the patient in the event of the patient deteriorating but they also worried about the impact such information might have on family members, which was identified as more of an issue for younger less experienced staff and highlighted the need to consider specific support for this group. Périer et al (2013) suggest that the ‘strength of emotions’ experienced by staff in their study may have been related to the fact that the study was conducted shortly after introducing diaries in the ICU and the whole ICU team being involved in keeping diaries. However, as discussed similar findings were reported in the current study from an ICU where diaries were well established, nurses were the only members of staff who co-authored the diary with family members and there was variation in age and ICU experience of the nurses interviewed.

It is recognised that the work nurses do is emotionally complex and nurses have an ability to present themselves in different ways, moving between different ‘faces’ to manage the emotional demands placed on them in their daily work (Bolton, 2000;

Bolton, 2001). The occupation of nursing therefore requires extensive emotion work and as seen with nurses' experiences of diaries, emotional effort or work is involved in providing this nursing intervention in ICU, mainly in association with reading accounts written by family members. It has been found by Stayt (2009) that nurses in ICU invest and experience many emotions in caring for family members, which they often suppress in the clinical environment leading to an accumulation over time (Stayt, 2009). Sources of emotional stress for nurses in caring for family members include the significance of death, breaking bad news and interpersonal relationships. Findings from the current study around nurses' experiences of diaries and Périer et al (2013) highlight that diaries can create a source of emotional stress for nurses in ICU, therefore it is important to consider how nurses manage and regulate their emotions in the work they do.

Stayt (2009) reported that nurses used different strategies of 'Self Preservation' to create space (physical and emotional) between themselves and family members in the ICU, for example maintaining an emotional distance. The regulation of emotional space between nurses and family members or patients has been the main focus of a study by Hayward and Tuckey (2011). They identified nine different emotion regulation strategies used by nurses, including emotional boundaries which nurses used to regulate 'anticipated', 'evolving' and 'felt' emotions. Emotional boundaries were portrayed as

*"...an emotional force field manipulated to influence the nature, intensity, and duration of emotions experienced at work." (p. 1511)*

Hayward and Tuckey (2011) found that the emotional boundaries represented a broader approach to the way nurses worked in terms of interacting with and relating to patients and families, to the extent that emotional boundaries develop into part of the nurse's professional identity, similar to wearing a uniform. Nurses were able to control, between themselves and family members or patients, the amount of emotional distance or connection they had at any given time. Creating space or distancing allowed nurses to protect their emotional resources while connecting or investing their emotional selves helped to develop relationships (Hayward & Tuckey, 2011). Nurses may develop and use emotional boundaries as a strategy to regulate



their emotions and protect themselves when interacting with diaries, as the diary represents the critically ill patient and their family members during the time in ICU. While this section on Emotion has highlighted the emotional effort involved for nurses the following section on the theme Person Centered will demonstrate how connecting with patients and family members from reading or writing in the diary can be beneficial to all those involved.

The experiences of emotional effort and emotional support associated with reading and writing in critical care diaries are different for each individual, demonstrated and discussed across and within the groups of family members, patients and nurses. Whilst Plummer's (1995) model does not explicitly identify emotion as an aspect associated with jointly creating a story it does take into account the people and events the diary or story is written about and the context in which it is written. With regards to the activity of reading a story Plummer states:

*"Sometimes a text is read in relative isolation and sometimes it is read through a social world or an imagined community – of class, of race, of gender, of experiences, of taste. Sometimes people hear so lightly what others say so intensely, and sometimes people hear so intensely what others say so lightly." (Plummer, 1995, p. 21)*

The diary and story of what happened concerns the experience of critical illness, the critically ill patient and all significant others involved, whether present or not (determined by producers of the diary). The story is created in, and thus influenced by, the interactive social world of ICU where emotions run high and distressing events occur, some of which are selected and recorded by producers of the diary who also become consumers during the time in ICU. Therefore, entries written for the patient or primary consumer of the diary can directly affect others who read this.

In later work, Plummer discusses the consequences of stories stating that stories

*"...can turn personal chaos into order. They can help us to make sense of our lives and the world around us; and in times of crisis, they can help repair damaged lives." (Plummer, 2013, p. 211).*

With regards to critical care diaries this begins in the ICU with the family writing in and reading the diary whereas patients start this process later on in their recovery

through reading the diary. Through the activities of reading and writing the diary, or story of what happened, people find meaning and understanding around their experiences and others.

*“Good stories are our good friends, our best friends, trusted and true. Bad stories are our traumas, problems and fears. Stories can make life easier; but they can make it harder too.” (Plummer, 2013, p. 211)*

We cannot forget that diaries contain emotional information and a certain amount of emotional effort is required to read and write in the diary during and after the time in ICU, experienced by family members, nurses and patients. Furthermore, the experience of critical illness is different for all those involved and although similar experiences may be found in each group, every person and every diary is different. Therefore, helping to explain why nurses in this study did not experience emotional support from the diary, as although nurses are witness to the critical illness journey and are part of it, they do not experience critical illness in the same way that patients and family members do.

In summary, emotional support was experienced by family members from reading and writing in the diary during the time in ICU and by patients reading the diary after the time in ICU. Reading and writing in the diary gave family members hope in a world of uncertainty and helped them to express and share their thoughts and feelings as well as get their emotions out, which had a positive effect. Patients experienced the diary as a positive and important support during their recovery from learning about what happened to how much people cared and who had been there during this time. However, this study highlights the emotional effort experienced with reading and writing a diary, especially during the time in ICU with family members and nurses which has previously received little attention. Furthermore, within each group of family members, nurses and patients it would appear that certain individuals may find it particularly difficult or challenging to interact with the diary. For example, family members in ICU who are too upset or do not know what to write, younger less experienced staff and patients who may find it difficult to come to terms with certain aspects of their ICU experience. This demonstrates a need to support all those involved with critical care diaries and further research to identify and understand

what support each group may require. However, keeping in mind that every person brings with them different experiences and each diary created is unique.

## 5.6 Person Centered

Diaries promoted a more person centered approach towards caring for patients and families in the technological environment of ICU. Diaries were viewed by patients, family members and nurses as an important aspect of care given in ICU, although a distinction was made by nurses between diaries and the more technical aspects of care. Family members and patients appreciated the effort made by nurses taking the time to write in the diary, which gave a more 'personal touch' to caring. Finally, information contained in the diary gave others reading it a better insight into the identity of the patient, nurses and family members.

Diaries were integrated into the care provided for patients and family members in ICU, having been established for a few years prior to the study starting. Patients and family members accepted the diary as part of the ICU 'package' and 'took it for granted' that this is what happens in ICU. Whereas some nurses spoke about their initial thoughts around diaries before they were introduced in the unit, making a distinction between diaries and the more technical aspects of nursing care provided in ICU at that time. Diary writing was a regular activity performed by nurses and valued as an important aspect of care. However, when asked directly, nurses did not believe that the diary changed or made a difference to how they 'actually' cared for patients.

Diaries have been described and interpreted as an 'act of caring' (Gjengedal, et al., 2010; Egerod, et al., 2011a; Ewens, et al., 2014; Glimelius Petersson, et al., 2015) and a 'caring activity' involving writers in a common shared activity (Roulin, et al., 2007). However, diary writing was 'not a priority' for nurses who spoke about running out of time or forgetting to write in the diary when they had a busy shift or were caring for a patient who was 'really sick'. Locke et al (2016) reported similar findings from nurses involved in an ICU diary program who regarded writing diary entries as

*“...one of their last priorities, especially when staffing was low or the patient workload was increased.” (p. 218)*

Family members and patients appreciated the effort nurses made by writing in the diary, which meant a lot even if an entry was quite small. Whilst experienced and accepted as part of the care provided in ICU, it was recognised by family members and patients that nurses in the unit were busy yet they made time to write in the diary and did this without even knowing the patient

*“...they’re putting lovely wee quotes in at the end of it...for somebody to not know, you know tae accept somebody that they’ve never met before and feel that for somebody...” (Angela FM1).*

Making the effort and finding time to write in the diary has been described as going ‘above and beyond’ the expectations of patients and family members, with regards to the clinical service and duties performed by staff in ICU (Storli & Lind, 2009; Ewens, et al., 2014). However as seen in this study, although patients and families appreciated the effort made by nurses, the diary was very much accepted and experienced as part of the care they received from nursing staff during and after the time in ICU.

From the act of nurses writing in the diary Johansson et al (2015) reported feelings generated between family members that

*“...the patient was unique as a person and was being cared for and valued.” (p. 6)*

Whereas Glimelius Petersson et al (2015) reported from patient experiences that the diary showed many people cared. Similarly, in this study the act of writing in the diary or taking the time to write was associated with caring. However, from the patient perspective it did not matter who had written in the diary,

*“Whether it be family, whether it be nursing staff doesn’t matter it’s the fact that people care...they take the time to write something in that so yes they care.” (Alison P4).*

As highlighted, nurses prioritised other aspects of care before writing in the diary, meaning that sometimes an entry for a shift would be missed or forgotten. Whereas

some family members, as discussed in the theme emotion, found it too difficult to write in the diary during the time in ICU. Therefore, not writing in the diary does not necessarily mean that people do not care, which might be helpful to explain and make patients and family members aware of this when they are reading or looking for entries written in the diary.

The diary demonstrated a more ‘personal touch’ or approach to caring for the patient in ICU by respecting and addressing the patient individually as a person. A simple act such as addressing each diary entry to the patient by using their first name or signing off an entry with the nurse’s own name made the diary personal. No other document exists addressing the patient directly in a personal and supportive manner about their experiences and events occurring in ICU (Egerod & Christensen, 2010). As a nursing intervention the diary has been promoted as patient centred, written to and for the patient personally, thus acknowledging and creating a link to the ‘patient as a person’ in ICU (Roulin & Spirig, 2006; Roulin, et al., 2007; Gjengedal, et al., 2010).

Writing in and reading the diary requires the nurse to connect with and focus on the sedated critically ill patient as a person. It also provides a means for the nurse to communicate with the patient, involve the family in care and thus develop a therapeutic relationship with the family and patient (Egerod & Christensen 2010). As found in this study and others, inviting family members to participate with the diary not only involves them in care but also helps to humanise the ICU experience (Périer, et al., 2013; Garrouste-Orgeas, et al., 2014; Nair, et al., 2015; Johansson, et al., 2015). The diary gives presence to family members in the ICU, provides a way for family members to communicate with the patient and can help support their emotional needs therefore facilitating nurses in providing person-centred care in this environment.

Person-centred care is concerned with

*“...treating people as individuals; respecting their rights as a person; building mutual trust and understanding, and developing therapeutic relationships.” (McCormack & McCance, 2010, p. 1).*

Providing person-centred nursing care is challenging in the ICU environment and different to other healthcare areas due to the characteristics of patients, the environment and the bio-psycho-social demands made on nurses (Jakimowicz & Perry, 2015). However, when effective this can have positive outcomes on patients, nurses and the service including patient experience, patient and staff satisfaction and retention of the nursing workforce (Jakimowicz & Perry, 2015). In the ICU patients are critically ill, requiring them to be sedated and ventilated and thus reducing their ability to communicate and interact with the nurse (Kelly, 2007). The nurse is involved in performing objective assessments of the patient to determine what support is required. The main focus of care is on improving the physical wellbeing of the patient through the provision of complex technical treatments and care, making it difficult for nurses to understand or engage in person-centred care in this environment (Kelleher, 2006). The patient's physical condition, and in particular their inability to communicate effectively,

*“...severely modifies and at times eliminates the possibility of the nurse establishing a mutual and meaningful relationship with the patient.”*  
(Kelleher, 2006, p. 36).

The presence of a therapeutic nurse-patient relationship is considered to be central to person-centred care however, this is dependent on the context in which the care is delivered (McCormack, 2004). It has been identified that a nurse-family relationship exists in ICU, often replacing the nurse-patient relationship (Hupcey, 1998). Strategies used by nurses to facilitate this relationship include: demonstrating commitment to the patient and family; persevering through getting to know the family, spending time with them and sharing information about themselves; and once the relationship with the family begins to develop, being involved with the family (Hupcey, 1998). The existence of this relationship is key to providing person-centred care in the ICU setting as existing evidence relating to the concept of person-centred care acknowledges the importance of forming therapeutic relationships between professionals and ‘significant others’ of the patient, as well as the patient (McCormack & McCance, 2006).

In this study, it was found that through reading the diary nurses got to know the patient and their family. However, getting to know the patient in ICU was an issue for nurses even with the presence of a diary and nurses reported often getting to know family members better and relied on family members for personal information about the patient. Nevertheless, nurses were able to gain an insight into what the patient was like as a person, the patient's family and what life was like for them outside the ICU from information written in the diary. Furthermore, writing in the diary made nurses reflect on the patient as a person and consider the identity of the person they were looking after. Writing in the diary has been said to keep nurses aware of the patient as a person and improve patient care by shifting the focus from a medical perspective to a more human perspective (Gjengedal, et al., 2010). Périer et al (2013) found from the perspectives of ICU workers, including nurses, that writing in the diary helped them to humanise their roles and reading entries written by family members widened their view of the family by learning about any concerns the family had as well as family members' feelings and commitment towards the patient.

Family members and patients believed that they could get to know the nurses from what had been written, which had a positive effect. Whereas, from a nursing perspective having an identity in the diary alongside the patient and their family made the care 'more personal'. Garrouste-Orgeas et al (2014) found that reading the diary changed family members' perceptions of staff, from healthcare professionals to people, through the consideration and support shown to patients as living human beings in the diary. This helped to humanise staff and patients in ICU as family members struggled to recognise their loved one when they were critically ill and connected to various equipment (Garrouste-Orgeas, et al., 2014). From the findings in this study getting to know the identity of the patient, family members and nursing staff through reading diary entries contributed to the experience of person centeredness in the ICU.

Plummer states that

*"...stories tell us what it means to be living and human." (Plummer, 2013, p. 211).*

The story or stories present in the diary allowed people to get to know and learn about others and the roles they performed during the time in ICU. Nurses gained an insight into patients, their family members and their world outside the ICU, whereas family members and patients got to know nurses. Furthermore, family members and patients learned about the world of ICU and the critically ill patient. Referring to Plummer's (1995) model, the diary or stories in texts is created from lives and events which Plummer acknowledges are unknown and unknowable however, from creating the diary people gain further insight into those lives and events. Whilst the diary represents the critically ill patient and is written to and for the patient, through the act of writing in and reading the diary the patient's presence and identity as a person is confirmed alongside family members and nurses in the ICU. Therefore, interacting with the diary focuses people (producers and consumers) on the patient as a person as well as each other during and after the time in ICU.

In summary, the diary was viewed and experienced as an important aspect of care delivered in ICU for patients and their family members. Writing in the diary was associated with caring, however as discussed, there are situations where it is not always possible for nurses and family members to write in the diary during every shift or visit to the ICU. The effort made by nurses to write in the diary, addressing the patient individually as a person, was appreciated by family members and patients. Writing in and reading the diary facilitated nurse-patient and nurse-family relationships in the ICU as the diary focused nurses on the patient as a person and involved family members in care. Furthermore, patients, family members and nurses got to know each other from entries written in the diary during the time in ICU, thus contributing to and facilitating person-centred care in this environment.

## **5.7 Gender**

From the findings in this study it became apparent that female family members were more likely to participate in diary writing in the ICU than male family members. However male family members read the diary when they visited. This was initially raised by nursing staff in the unit during informal conversations with the researcher and explored further in interviews with participants recruited later on in the study. Furthermore, the researcher found it difficult to identify and recruit male family



members involved in using diaries which in itself appeared to highlight a difference between male and female family members in the ICU and diary use. The focus of this section will therefore be on male family members and diary use in the ICU, which has not been previously reported with critical care diaries.

The issue of gender and diary use has been raised before by Egerod et al (2011b) who identified that findings from their study suggested 'gendered variations' in diary use after ICU. They found that some male family members and patients were not interested in their diaries and attributed this to differences in coping strategies between males and females. Hobfoll et al (1994), referenced by the authors, introduce the reader to a number of studies where it has been found that women are more likely to use 'emotion-focused coping' whereas men are more likely to use 'problem focused coping'. Therefore, if the diary is being used by family members as a way to cope or deal with the experience of critical illness during the time in ICU then it would appear to be feasible that gender may influence how the diary is used.

However, the 'gendered variations' in diary use reported by Egerod et al (2011b) apply to both family members and patients which is not consistent with the findings from this study, as in this study male patients wanted their diaries and were interested in what had been written. Furthermore, in the study by Egerod et al (2011b) family members were not invited to write in the diary thus influencing how the diary was used by family members in the ICU. However, it is not known if the male family members would have participated in writing during the time in ICU if they were invited or whether being encouraged to write would have made them more interested in the diary after ICU. Therefore, it is important to acknowledge the context in which the diary is used as this will inform and help to understand why it is being used in a particular way, or not being used at all.

In the current study, a male patient, Graham, who had previous experience with diaries when his wife was in ICU reported using the diary, as a family member, in a similar way to that described by female family members. Graham wrote in the diary when he visited, read diary entries from nursing staff to support his understanding of what was going on and read through the diary with his wife when she was recovering

at home. However, he did not mention using the diary for emotional support, which was frequently reported by female family members in the study.

Knowledge around the experiences of male family members with diaries is currently lacking. Early diary studies involving family members were mainly focused on the experiences of patients with diaries (Bergbom, et al., 1999; Bäckman & Walther, 2001). The gender of family member participants was not reported and the majority of family members taking part were those of non ICU survivors. In comparison, more recent studies have involved family members of ICU survivors. However, in one study, only the gender of patient participants was reported (Garrouste-Orgeas, et al., 2012), whereas Egerod et al (2011b) report the gender of both patients and family members. Recent studies focusing exclusively on family members and diaries have reported the gender of participants (Jones, et al., 2012; Garrouste-Orgeas, et al., 2014; Johansson, et al., 2015; Nielsen & Angel, 2015a). However, when comparing the sample groups of family members across the studies referenced, it is revealed that there are consistently more female family members recruited than males. Yet no explanations have been given by the authors as to why this is the case and as a result there are significantly more females than males represented in diary research with family members of critically ill patients.

From the researcher's experience, there appeared to be less male than female family members visiting in the ICU. Data from the Scottish Intensive Care Society Audit Group consistently shows that there are more males admitted to critical care units in Scotland than females. In the 2015 audit, reporting on data from 2014, 54% of admissions to critical care units were male with this increasing to 58% in ICUs and combined units. Furthermore, males accounted for 56.1% of ICU admissions with a length of stay greater than 2 days in ICU (Scottish Intensive Care Society, 2015). It could therefore be suggested that a greater number of males in ICU may account for there being more female visitors for example if the next of kin is the patient's spouse. However, in addition to this, finding a male family member who was using the diary and willing to be interviewed was difficult.

Patel et al (2003) note, with regards to challenges in recruiting research participants that some people or groups are harder to reach than others and one of the

characteristics associated with a poor response rate to research is the male gender. Other characteristics and recognised ‘socially disadvantaged groups’ include those people of older age, black and minority ethnic groups, low educational status, unemployment or low occupational status, low family income, smoker, substance misuse, recent illness or poor present health and high use of medical care (Patel, et al., 2003; Bonevski, et al., 2014). Therefore, it would appear that male family members can be more difficult to reach by the very nature of them being male and if other factors are present this may have an added impact on recruitment.

In a recent study exploring relatives’ perception of writing diaries for critically ill patients the family members of six patients were interviewed (Nielsen & Angel, 2015a). The gender of the related patients was equally mixed with three male and three female patients, however five of the six interviews were conducted with a single female family member who was either a wife, a daughter or in one family a sister. The other interview was with a son and daughter in law who were interviewed together. The diaries were written by one or more family members who were mainly female, which may also explain why more female family members tend to be recruited into research in this area.

Participants in the current study gave accounts of female family members becoming the main ‘spokesperson’ in ICU and taking the lead in their family with diary writing, including situations where the female was not the direct next of kin for the patient. This was experienced first-hand by the researcher when recruiting participants. Furthermore, differences between what male and female family members wrote, with regards to the length of the entry and the amount of detail included, were reported. Research looking specifically at the content and structure of diary entries written by nurses and family members (Roulin, et al., 2007; Egerod & Christensen, 2009) has not identified gender as an influencing factor on what is written in the diary and how it is written.

Di Gangi et al (2013) introduced an ‘ICU guest book’ for family members to write in when they visited ICU and using a mixed methods approach examined how informative the content of stories (entries) were with regards to family members’ emotional responses, needs, perceptions and satisfaction with care. The authors

believed that by choosing a guestbook this would encourage family members to share their thoughts and leave comments without having to identify themselves. However, 68% (118) of family members who wrote in the guest book were female and only 32% (56) were male which supports findings from this study that females take the lead when it comes to writing and are more likely to participate in writing during the time in ICU than males are. A number of observations (158) were missing where gender was not identified, so it is possible that more males participated than reported. Future research exploring the content of diary entries written by male and female family members may provide further insight into how the diary is being used by these groups during the time in ICU as well as exploring the experiences of male family members with diaries.

When searching beyond the critical care literature the issue of gender and diary keeping is not new. For example, in an article discussing the potential benefit of diary keeping for young gifted males an argument is made that diary keeping or journaling is portrayed in the media as a female activity (Heydt, 2004).

*“...no matter where one looks throughout different types of media...there is a strong sentiment that “journaling” is a cathartic, emotional, and sentimental activity reserved only for females.” (p. 16)*

Having found many references to diaries kept by females recounting their feelings (fictional and non-fictional) Heydt (2004) comments in his discussion on ‘Gender and Journaling’ that

*“Females of all ages seem to be encouraged by literature to pick up a journal and document their lives. Indeed, the words **diary** and **female** seem to be synonymous with one another.” (p. 17)*

Whereas trying to find examples of diaries written by males was more difficult.

*“The public portrayal of journaling for males appears to be reserved for the demented, the suicidal, or the psychopathic, rather than for the normal, healthy, self-actualising individual.” (p. 17)*

In the above quote Heydt (2004) refers to some of the diaries he found written by males and how these have been portrayed in public. So for example diaries written

during therapy sessions for traumatic experiences, diaries written by famous figures such as Kurt Cobain the musician who later committed suicide and personal accounts from high profile criminals convicted for multiple murders.

*“...males face the difficult decision between their masculinity (in the eyes of their peers) and sharing their feelings. They also struggle with the feeling they are not psychologically sound or the possibility that they can maintain their sanity through journal keeping.” (p. 18)*

The extent to which this can be applied to the current findings is questionable though as critical care diaries are written to and for the patient. Therefore, when family members are invited to write in the diary it is primarily for the patient and not themselves. However, Heydt (2004) does raise an important point for consideration, diary keeping generally appears to be associated more with females than males and therefore it may be seen as more acceptable for a female to write in a diary than a male.

Neilson and Angel (2015a) have found that writing in a diary during the time in ICU is one way to meet family members' needs in the 'critical situation'. Additionally, findings from the current study have shown that family members receive support in various ways from reading and writing in the diary. Therefore, male family members who do not use the diary may be missing out, as well as the patient who receives the diary with no entries from their family member. The story of what happened during the time in ICU from the perspective of the family member will be missing. If there is a difference in how males and females use the diary then gender specific advice for diary keeping may encourage males to participate by making the diary more accessible for them, or considering other ways to keep an account for the patient during the time in ICU may need to be explored.

The idea of creating gender specific services has been identified before in relation to male carers. A systematic review exploring the barriers and facilitators for male carers in accessing formal and informal support found that compared to females, males were less likely to access support services (Greenwood & Smith, 2015). Similar to research around experiences with diaries it was noted that research on carers experiences related mainly to females and numbers of female carers in the UK

were higher than males. From the available research, it was found that male and female carers had similar experiences although there were some differences which the authors identified could relate to 'gender roles'. Greenwood and Smith (2015) state:

*"Males are reported to adopt more independent attitudes and to take more task-orientated approaches to caring, when compared to female carers, who use more emotion-focussed strategies." (p. 163)*

Gender roles are those roles which women and men are expected to perform based on what sex they are, with the traditional view in many Western Societies that women are more nurturing than men (Blackstone, 2003, p. 337). Early work by the sociologist Janet Finch in her book 'Family Obligations and Social Change' (Finch, 1989) identifies different types of support family members (kin) provide for each other and discusses in detail the different relationships providing mutual support to one another for example from a parent to a child or between a brother and sister. Five main types of support were explored: economic support; accommodation; personal care; practical support and child care; emotional and moral support. When it came to variations in the experience and patterns of kin support, gender was found to be an important factor. However, the gender differences in kin support were not fully explained by the cultural definitions of men's and women's 'business' or in other words traditional gender roles. Three other influencing factors emerged. Men and women had different access to resources e.g. financial, they had different responsibilities in the division of domestic labour such as providing child care and their lives in general are said to be organised differently in society (Finch, 1989, p. 53). Furthermore, women appeared to be more available when it came to providing help requiring the contribution of time and 'domestic labour'. Other issues influencing the experience of kin support were social class, ethnicity and the area or region where families lived.

In this study, participants gave further insight into reasons why male family members did not contribute to the diary, which were not necessarily related to gender. Influencing factors such as age and ability to write were discussed in relation to how the individual family member was coping with the situation. Fiona, one of the

nurses, spoke in detail about experiences she had with older male family members visiting in the unit and how they often made comments about not doing the writing, not being good at writing or having difficulty with spelling. From her experience, older men in particular were very aware of their writing abilities. However, Beth another nurse who had cared for a patient and family recruited to the study reported that a younger male family member was finding it difficult to cope with the situation so did not visit very often and when he did he was only in the unit for a very short period of time. This was confirmed by the account his sister Katrina gave. Therefore, age as with gender does not necessarily determine whether someone will write in the diary or not. However, having the ability to write and being confident to write in a diary that other people have access to would appear to have an influence.

Nurses commented on the level of literacy in the area where the ICU was situated as being a particular issue for diary use and although given as a reason for males not getting involved with the diary, this applied to females as well. The study was conducted in an ICU situated in an area of Scotland considered to have a high proportion of deprivation, as reported in the Scottish Index of Multiple Deprivation (SIMD, 2012).

*“...xxxx is the constituency in the xxxxx region with the highest proportion of its datazones in Scotland’s 15% most deprived...”*

The Scottish Index of Multiple Deprivation (SIMD, 2012) identifies areas in Scotland where there are ‘*concentrations of multiple deprivation*’, measuring different aspects including employment, income, health, education, crime, access to services and housing. Therefore, concerns raised by nurses about levels of literacy in the area where the ICU was situated would appear to be supported given that this area has high levels of deprivation and there is a direct link between poverty and illiteracy (World Literacy Foundation, 2015).

Six to eight million adults in the UK are estimated to be ‘functionally illiterate’, meaning that although they have basic reading, writing and numeracy skills they are unable to apply these to everyday tasks such as reading a medicine or food label or completing an application form (World Literacy Foundation, 2015). The *Literacy*

*Commission Scotland: A Vision for Scotland* report found that 1 in 5 adults in Scotland had difficulties with reading and writing stating that ‘one fifth of Scottish adults do not have the literacy skills they need for their daily lives (Literacy Commission Scotland, 2009). Low levels of literacy are associated with low levels of employment and those who are employed are more likely to be in manual jobs (World Literacy Foundation, 2015). As noted by Fiona the nurse who spoke about experiences with older male family members, many of these men had left school at an early age and worked in manual jobs for most of their lives where they did not write on a daily basis and their wives took on responsibility for writing activities.

Low levels of literacy can lead to poorer health as

*“Illiteracy significantly limits a person’s ability to access, understand and apply health-related information and messages.”*  
(World Literacy Foundation, 2015, p. 7)

In a study by Easton et al (2013) the ways in which low literacy can lead to poor health as well as how to improve health services were explored from the perspectives of people with low literacy. It was found that in addition to the difficulties people can have with written information, spoken interactions with healthcare professionals were also an issue. Participants were reluctant to disclose to health professionals any literacy difficulties they had due to the stigma associated with low literacy. They tried to conceal this by making up excuses for not reading information and limiting conversations with health professionals. Participants spoke about becoming anxious and making excuses to leave anytime they were asked to complete a form or if a health professional produced any paperwork during a consultation. Suggestions made by participants to improve health services were to educate staff about literacy problems, simplify written information and explain clinical information in lay terms (Easton, et al., 2013). The diary can help family members’ understanding of information during the time in ICU as it is written in everyday language using lay terms and can be read or referred to more than once which helps family members to ‘assimilate’ the information (Garrouste-Orgeas, et al., 2014). However, having a diary in ICU at the patient’s bed space and encouraging family members to write in it every time they visit may lead to increased levels of anxiety for family members, if



they have difficulties with literacy. Likewise, a similar situation could occur with patients when the diary is handed over after ICU.

Plummer's (1995) model does not specifically identify gender as an influencing factor in 'Stories as joint actions'. However, it does take into account the context in which stories are created, namely the 'interactive social worlds and 'negotiated networks of collective activity', as well as those producers who create them. These findings inform Plummer's model when applied to the creation of diaries in the ICU and highlight the issue that male family members may not wish to engage in the joint action of creating a diary, for whatever reason. Factors influencing participation in diary writing as discussed are not necessarily gender specific and can be influenced by the wider culture in which this activity takes place including the patient's family network, the ICU environment and experience of critical illness or the geographical area. As reported in the section on emotion, some family members were too upset to write, relating to the situation of having a loved one who is critically ill in ICU.

Whereas in this section on gender, broader issues including the level of literacy in the area of Scotland where the study was conducted appeared to be an issue which not only has an impact on invited producers of the diary but will likely affect consumers to, whether they are male or female. Nurses as the main producers of the diary take on the roles of coaching and coaxing people to tell their stories, as identified in the information section. However, if writing is not the preferred method for an individual to tell a story this will ultimately have an influence on the content of the diary and the story of what happened to the patient when they were in ICU.

Furthermore, the support that family members receive from interacting with the diary will not be available to those who are unable or do not wish to do this so other methods may need to be explored for example to support male family members during the time in ICU.

In summary, male family members were difficult to recruit to the study and it became apparent that males were less likely to write in a diary than females, however they did appear to read the diary. This created gender imbalance in the sample of family members and on further investigation into existing diary research, in particular, research with family members, it was noted that female family members

were over represented in sample groups. More males are admitted to ICUs than females which may account for more females visiting in the ICU however, finding a male family member who was using the diary and willing to be interviewed was difficult. Possible reasons why male family members were less likely to participate in research were explored and from this, males were identified as a hard to reach group along with other factors which may influence recruitment to research (Patel, et al., 2003). Further evidence of males being less likely to participate in writing activities in the ICU was found (Di Gangi, et al., 2013) and general discussion around males and diary keeping presented (Heydt, 2004). Gender differences in family support were discussed and findings from study participants on reasons why male family members were less likely to write diaries were considered, which uncovered other important influencing factors including the level of literacy in the area where the study was conducted. Therefore, in addition to gendered differences in behaviours around expressing emotion in general and in particular through writing a diary, socio-demographic factors such as social deprivation and educational status, impacting on literacy levels can reduce the likelihood of male family members and female family members keeping a diary during the time in ICU.

## 5.8 Chapter summary

In this chapter, the research findings have been discussed using the emergent themes of Information, Presence, Communication, Emotion, Person Centered and Gender. Plummer's (1995) model of 'Stories as joint actions', introduced at the beginning of the chapter in Figure 24, has been referred to throughout in relation to each emergent theme to build up and support discussion of the findings. 'Stories as joint actions' will be revisited again following this summary section to conclude the discussion chapter

In summary, critical care diaries are co-created by nurses and family members who are the main producers of the diary. Other producers include family members unable to visit in ICU and the patient or intended consumer of the diary. Nurses as the main producers take on the roles of coacher and coxer through encouraging, advising and guiding others to write. Producers had an awareness of the patient eventually reading the diary which meant decisions about what (content) and how (presentation)

information was written were based on beliefs of what might be of value to the patient. Information in the diary was helpful for patients recovering from critical illness to fill in gaps from their time in ICU, a process likened to putting together a jigsaw puzzle. Patients as consumers constructed their own story of the time in ICU from the diary or ‘stories in texts’. Whereas family members as producers of the diary simultaneously became consumers by actively reading information contained in the diary to support their own informational needs during the time in ICU. However, it became apparent that the consequences of the story or stories told in the diary did not always align with making sense of and understanding the ICU experience.

Diaries gave presence to patients in the ICU, when they were unable to determine or assert this for themselves, as the diary was written to and about the patient. The activity of writing undertaken by producers of the diary situated family members, friends, nurses and other healthcare professionals with the patient in ICU, including healthcare staff from other areas and family members who were unable to visit meaning that presence documented in the diary extended beyond producers and consumers of the diary. Therefore, presence was shared in the diary with those who entered or were already members of the ‘interactive social world’ of ICU or those who were temporarily associated with this world through the patient being critically ill, including people from the many different interactive social worlds of the patient and ‘negotiated networks of collective activity’ such as the patient’s family.

Having established the patient’s presence, the diary became a platform for communication interactions between producers, consumers and others during and after the time in ICU. Family members experienced the activity of writing or producing the diary as talking or having a conversation with the patient when there was no other way. Through writing, ‘the unspoken word’ containing thoughts and feelings not normally said out loud or shared was expressed. Nurses, the main producers of the diary, became consumers by referring to information in the diary to enhance communication with patients and family members in ICU. Patients read and referred to their diary to talk through events with others and the diary acted as a tool for communication, initiating and opening up conversations. While diaries are created to give the patient an account or story of what happened in ICU, thus

supporting patients in their recovery from the experience of critical illness, findings from this study show that diaries are used by family members, nurses and patients to facilitate communication during and after the time in ICU. The diary is more than 'stories in texts', with people in the diary and the diary coming alive through the interactive process of communication whether that be written or spoken.

Interacting with the diary was associated with emotional effort and emotional support for producers and consumers of the diary during and after the time in ICU.

Emotional support was experienced by family members from reading and writing in the diary during the time in ICU whereas patients experienced emotional support from reading the diary after the time in ICU. A written account of the patient's critical illness journey in ICU enabled family members to see progress while patients who read this after the event learned about what had happened. Reading about thoughts and feelings shared in the diary demonstrated to patients and family members that people cared. Additionally, family members spoke about the importance of the diary in supporting them to express through writing their thoughts, feelings and emotions. However, emotional effort was experienced by patients, nurses and family members. Therefore, it is important to consider what support people may need as well as looking at further research into identifying those who may find it particularly difficult or challenging to interact with a diary either during or after the time in ICU. Writing and or reading about events and emotions relating to a person experiencing critical illness can be associated with experiences of emotional effort and support, during and after the time in ICU.

The diary promoted a person centered approach to caring for patients and their family members and was viewed as an important aspect of care, delivered in the ICU. However, it was not always possible to write in the diary during every shift or visit to the ICU, with clinical care taking priority for nurses and some family members being unable to visit or too upset to write. Family members and patients appreciated the time and effort people put into writing in the diary and associated the act of writing with caring for the patient, which makes it important to ensure patients and family members understand that it is not always possible for people to write an entry in the diary every day and if people have not written in the diary it does not

mean that they do not care. Patients were the central focus of the story written in the diary and their story was written directly to them. Through this presence in the diary the patient was recognised as a person in the ICU. The act of jointly creating the story involved family members in care, which in turn helped to facilitate nurse-patient and nurse-family relationships in the ICU as the information written was focused on the patient as a person. Through reading this information patients, family members and nurses got to know each other, thus enhancing patient and family person centered care in the ICU.

As discussed in this chapter male family members were less likely to write in the diary than females, leading to the issue of gender and diary use. Male family members were difficult to recruit and less willing than female family members to be interviewed, resulting in a gender imbalance in the sample of family members. However, it became apparent that male family members have been underrepresented in diary research, which should be considered when designing future research into this area, especially if the focus is on family members and diaries. As highlighted from the literature and the findings of this study, males have been identified as a hard to reach group in research and possibly less likely to participate in writing activities in the ICU. Other factors such as gender differences in family support, how people express their emotions and the level of literacy in the area where the study was conducted were considered to explain this further. Furthermore, socio-demographic factors influencing literacy levels may reduce the likelihood of any family member keeping a diary during the time in ICU. Therefore, such factors must be given careful thought when developing or investigating interventions to support patients and family members.

## **5.9 Critical Care Diaries as joint actions**

To conclude, Plummer's model 'Stories as joint actions' (Plummer, 1995) presented in the introduction, see section 5.1, has been adapted to create a new conceptual model 'Critical Care Diaries as joint actions', see figure 25.

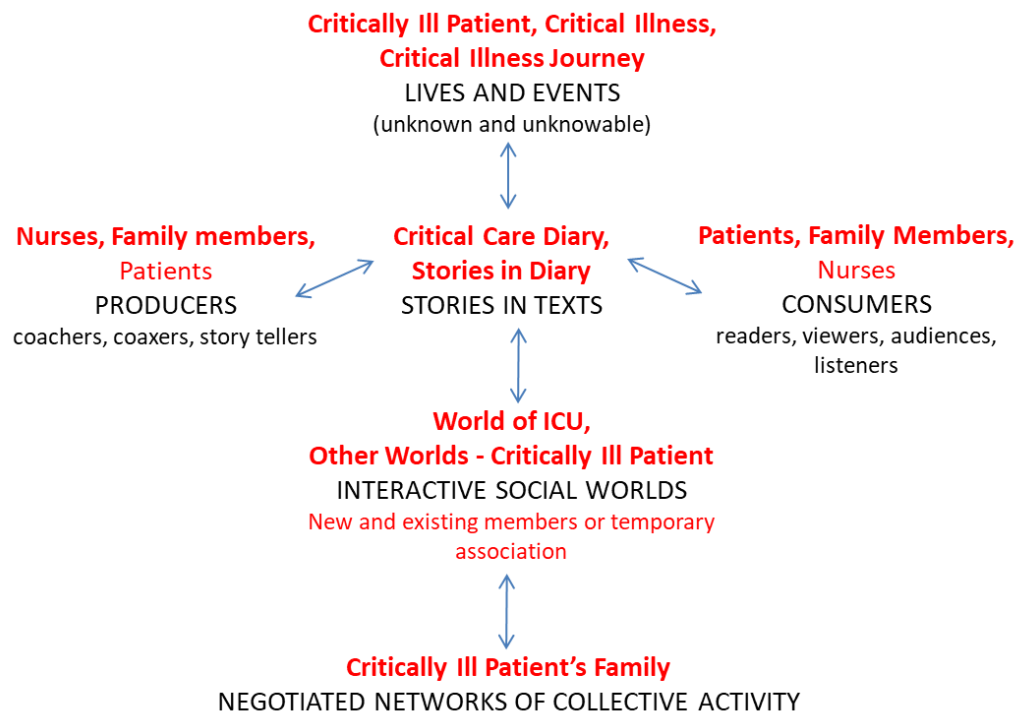


Figure 25: *Critical Care Diaries as joint actions, adapted from Stories as joint actions (Plummer 1995, p. 23)*

**LIVES AND EVENTS** include the lives of all those involved or connected to the critically ill patient, the critical illness and the time spent in ICU, however this time-period extends further into the patient's recovery from the critical illness. Lives and events are unknown and unknowable, providing the main foundation for the creation of the critical care diary and incorporating other people and events throughout the critical illness journey, continuing while the diary is being written and read.

**STORIES IN TEXTS** represents the diary as a story and the different intertwined and interconnected stories running through the diary. For example, in the broader sense, stories in texts can be the story of the patient's journey through the critical illness including stories of family members and their experience of coping with a critically ill relative or stories specific to one particular aspect of the patient's critical illness experience as told by a nurse or family member. There are stories within stories, dependent on what lives and events are being described as well as who is writing and reading the diary.

**PRODUCERS** of the diary can take on different roles, for example, as coaches, coaxers, coercers and story tellers. Whereas **CONSUMERS** can be readers, viewers, audiences and listeners. The idea of having producers and consumers of the diary, which in its most basic sense includes those who write and read in the diary, allows further exploration into how the diary is experienced by patients, family members and nurses. The findings from this study suggest that patients, family members and nurses can all be producers and consumers of the diary, taking on one or more of the roles listed. However, being a producer or consumer of the diary at different times and how this is experienced is dependent on each individual patient, family member and nurse as well as other contextual influencing factors. Such factors are not necessarily permanent and may relate to the environment, a situation, an individual, a group or the diary. For example, the workload in the ICU on a certain shift may have a direct impact on the ability of the nurse to write in the diary on that day or the emotional status of the patient or family member may prevent them from reading or writing in the diary. However, other less obvious factors should be considered such as male family members or patients and family member's ability to read and write.

The final parts of the model, **INTERACTIVE SOCIAL WORLDS** and **NEGOTIATED NETWORKS OF COLLECTIVE ACTIVITY** are more difficult to separate as they feed into one another, as well as the stories in texts. The main interactive social world where the diary is created is the world of ICU, which through the diary, links into other worlds and networks such as the patient's family. Acknowledging the wider culture and context in which critical care diaries are situated has enabled an in-depth exploration into patients', family members' and nurses' experiences and perspectives of critical care diaries. Plummer's model 'Stories as joint actions' (Plummer, 1995) has been adapted to create a new model 'Critical Care Diaries as joint actions' which provides new theory to explain and understand experiences with critical care diaries.

## Chapter 6 Conclusion

In this final chapter, limitations of the PhD study, implications for practice and suggestions for future research will be considered. Limitations of the study include issues around the research site, the study sample and data collection techniques. Implications for practice mainly relate to our current understanding of diaries. Whilst our current understanding is that this is something that is targeted at and provided for patients, this study shows that it clearly has an impact on other individuals involved. Finally, recommendations for future research arising from the findings of the completed PhD study will be outlined.

### 6.1 Limitations of the study

The main limitations of this study, identified by the researcher, relate to the research site, the study sample and data collection techniques. Each limitation is introduced and where possible examples are included, justification given for why this occurred and discussion around the potential effect of this on the study.

#### 6.1.1 Research site

The study was conducted in one small Scottish ICU. This might potentially be viewed as a limitation as the size and location of the ICU does not necessarily represent other ICUs in Scotland or in the UK. However, at the time of designing the study it was noted that very few ICUs in Scotland were using diaries, this was a relatively new practice on which there had been no previous research conducted. This supported the decision to conduct the study in Scotland. Furthermore, the primary aim was to gain an understanding of the experiences of diaries and therefore this study was exploratory and qualitative. The ideas, concepts and theories developed are transferrable to other similar situations as the research has been developed and written up in a transparent and detailed way. Therefore, supporting and demonstrating the methodological and analytical quality and trustworthiness of the research.

There is significant variation in the way that diaries are used, for example from the patient groups who receive diaries to how and when diaries are handed over to patients. In the unit where the research was conducted photographs were not



provided as part of the diary intervention. Therefore, the diaries in this ICU are different to some ICUs who use photographs. While this may potentially be viewed as a limitation it should be noted that many units do not use photographs and as reported in the Findings chapter, the written content of diaries from this unit was like that described in the diary literature. Furthermore, one major advantage this study has over other studies is that diaries were already established and embedded in clinical practice within the ICU and therefore not driven or influenced by a research protocol. Thus, it was possible to explore experiences of diaries in the context of how they are provided and used as part of an existing clinical service.

### **6.1.2 Study sample**

The study sample included a small number of patients, family members and nurses, allowing for an in-depth exploration of the experiences of diaries from multiple relational perspectives. However, the small numbers in each group might be considered a limitation of the study. Although the study was undertaken as a PhD research project it would have been possible to include larger numbers in each group if the researcher had focused on only one or two out of the three groups. As identified in the Literature Review chapter, patients, family members and nurses are the main people involved with diaries, so to gain an understanding on the phenomenon of the experiences of diaries it was important to include these three groups.

Another issue with the study sample was the mix of male and female participants, with more female participants recruited than males. When broken down into groups the main group where this was an issue was with family members, where all 6 family members recruited for interviews were female. Identified as a potential issue during the process of recruitment, attempts were made by the researcher to recruit male family members which, as outlined in the Research Design and Methods chapter, was not possible. There was however a unique situation in this study whereby one of the triads including a male patient and female family member had dual experiences with diaries from being both a patient and family member in the ICU. This situation gave some insight into the male family member experience, in addition to accounts

from other participants. However, the lack of male family members is still recognised as a limitation of the study.

With regards to the other sample groups, it is recognised in the nursing profession and represented in the ICU where the research was conducted that significantly more female than male nurses were employed, reflected in the sample with 5 female nurses and 1 male nurse recruited. Whereas for patients, a higher percentage of males than females are admitted to ICUs in NHS Scotland. The sample group of patients included 3 males and 1 female. Additionally, there were two further patients identified, male and female, who were unfortunately unable to participate.

Early diary studies involving family members tended to only include bereaved family members, thus ignoring family members' experiences with diaries in the ICU, where they often co-author the diary with nurses. This study excluded bereaved family members to explore this area further, which the researcher acknowledges may be viewed as a limitation to the sample group. Furthermore, the study was designed to incorporate different experiences of critical care diaries. However, the sample group was limited to those who interacted with the diary, whether through reading or writing in the diary. Therefore, experiences of family members who found it difficult to write in the diary or nurses who did not agree with this practice have not been explored.

### **6.1.3 Data collection techniques**

Limitations of the data collection techniques adopted in this study relate to the use of focused observations and photographs of diary entries which although were not considered as the main methods of data collection were limited and will therefore be discussed.

The opportunities available to the researcher to perform focused observations were limited due to the level of consent approved by the NHS Research Ethics Committee (REC), the unpredictable nature of diary related activities occurring and the availability of the researcher. For example, the researcher was unable to observe any examples of the initial introduction of diaries to family members in the ICU. This often took place at the bedside, which meant that the patient was present however

they did not have capacity to provide an informed consent giving the researcher permission to observe the nurse. Additionally, the activity was dependent on when the bedside nurse deemed it appropriate to introduce the diary to family members and as this was tailored to each individual family and situation, it was difficult to predict when this activity might happen. The researcher acknowledges that she could have returned to the REC and submitted an amendment to request proxy consent from family members on behalf of the patient, however this would have placed an additional burden on family members in the ICU with two consent approaches to observe the nurse performing one activity. Furthermore, it was possible to explore this aspect of diaries from the viewpoints of nurses and family members in the interviews.

Taking photographs of written diary entries was planned to provide examples that could be shared to introduce people to the concept of a critical care diary, as this is not routine practice in all ICUs. However, the photographs became an important aspect of the data collected and presented in the findings chapter, especially when referring to the information contained in the diary in the Findings chapter. To be able to access and photograph diary entries the researcher required consent from both the family member and the patient being interviewed, unless the patient had died. However, when faced with this situation the researcher decided it was not appropriate to request permission to access a diary from a grieving family (who had already consented and been interviewed), where the patient had died at home after being in the ICU. Whereas if a copy of the diary had been kept at the site, which happens in some ICUs, the researcher would have considered accessing this for example diary entries. Therefore, it could be argued that the range of diary entries collected was limited, however as discussed, this data collection technique was undertaken only to provide examples of diary entries and not as the main method of data collection or for analysis.

The main method of data collection was semi-structured interviews and as detailed in the Research Design and Methods chapter participants were recruited in a triad. While this was a unique approach to conducting research in this area there were occasions when a triad could not be completed. While related family member and

patient accounts of experiences were based on the one diary, nurse accounts were not. On reflection, this is not surprising as nurses care for many different patients and families in the ICU and therefore their experiences of diaries incorporated many different situations. However, some experiences discussed by nurses related directly to the family member and patient in the same triad.

## 6.2 Implications for practice

The main aim of this study was to gain a greater understanding into patients, nurses and family members experiences of critical care diaries. Findings from this study have provided valuable insight into the different ways in which diaries are experienced and used by these groups during and after the time in ICU. Although the diary is primarily written to and for the patient, family members, nurses and patients use the diary in different ways to support their needs and others needs throughout the experience of the critical illness. The conceptual model of ‘Stories as joint actions’ has provided new insight and understanding into experiences of critical care diaries. Developing and explaining the new model ‘Critical Care Diaries as joint actions’ has demonstrated different aspects of how diaries are used and experienced by patients, nurses and family members during and after the time in ICU. The implications of these findings for practice will be considered by highlighting and discussing some of the key findings.

One of the most significant findings of this study was that family members reported using the diary to support their own needs during the time in ICU. Therefore, as presented in the discussion chapter family members are consumers of the diary as well as producers. This along with other findings has several implications for practice as previously the focus has been on patients.

Information written in the diary was read by family members in the ICU and patients after ICU to make sense and come to terms with the experience of critical illness. Whilst it was already known that the diary provided information to patients after ICU, findings from this study have demonstrated that family members read entries written by nurses and sometimes other family members in the ICU to help them make sense and reflect on the situation. Nurses and family members reported writing

in the diary knowing that the patient would read this during their recovery therefore, consideration should be given to family members reading this in the ICU. For example, it is important for nurses to ensure family members are informed of any significant events occurring which have been documented in the diary before they read this. One family member was quite upset reading unexpected information in the diary about an acute deterioration in her husband's condition overnight that she did not know about until reading it in the diary. Likewise informing patients about what they may find in the diary is important too.

In addition to diaries, this finding can be applied more broadly by recognising that we need to support the information needs of family members as well as patients admitted to an acute or critical care area. Looking at ways to provide information for patients and family members is important and from this study the value of personalised information, available during and after the time in ICU, has been highlighted. Methods may include diaries, daily update sheets for patients and families in the ICU or discharge summaries as well as the provision of more generic information.

Some patients expressed that they would have liked more information in their diary, which has previously been reported in the diary literature. Careful consideration was given by nurses and family members to what information was included in the diary and how this was written. It should therefore be made clear to patients when they receive their diaries that whilst the diary represents the time they spent in ICU this is written voluntarily from the perspectives of nurses and family members and may not contain all the information the patient wants or needs. Furthermore, family members reported writing less in the diary as the patient began to waken in the ICU.

Therefore, consideration should be given to what information is recorded in the diary at this stage, as although patients may be awake they might not remember information and conversations from this time in the ICU. This again ties in with the point raised in the previous paragraph on how we provide personalised information for patients.

The diary was used by nurses, family members and patients as an aid to communication during and after the time in ICU. Diaries can support family

members to continue communicating with their loved one in the ICU when they are unable to respond. Additionally, as found in this study diaries have the potential to facilitate and improve communication interactions between nurses, family members and patients during and after a stay in ICU. One of the most important aspects of the diary for patients and family members was that it gave family members a way to communicate with their loved one in the ICU. In practice, whether diaries are implemented or not, if we introduced family members to the idea that writing is one way they can continue to communicate with their loved one when they are critically ill, for some family members and patients this may be beneficial.

Diaries can promote a more individualised or person centered approach towards caring for patients and families in the ICU environment. ICU nurses care for patients and their families in a highly specialised technical area. When diaries were integrated into the care provided patients, family members and nurses experienced care as personal and tailored to the individual. This experience came from writing in and reading the diary which assisted in getting to know the identity of the patient, family members and nursing staff in the ICU. Furthermore, the diary established the critically ill patient as a person, with diary entries being written to and for the patients in ICU as if they were there and able to respond.

Patients and family members received emotional support from reading and writing in the diary. The introduction of diaries or a similar intervention encouraging family members to write may support families emotionally in the ICU and could be considered in other areas or situations. The diary involved family members in care, helping them to feel included by giving them a purpose when they visited, the diary also acted as a distraction from the current situation. Despite experiencing such support, family members reported that the diary was not meant for them. Therefore, if diaries are to be promoted in this way, family members need to be informed that it is acceptable for them to use the diary to support their needs as well as their loved ones needs.

In contrast to the emotional support experienced, all three groups experienced emotional effort from writing in and reading the diary. Co-authoring diaries in the ICU with family members, in addition to the time commitment, can add to the

emotional work of nurses. Emotional effort was also experienced by patients, especially when reading the diary for the first time. Thoughts and feelings written by family members were partly responsible for the emotional effort experienced by nurses and patients, in addition to nurses not knowing what to write about difficult situations and patients learning about how unwell they had been. Therefore, in implementing critical care diaries consideration should be given to how to support nurses and family members as well as patients.

Some patients were found to write in their diary therefore as seen with family members and nurses, patients can be producers as well as consumers of the diary. However, this is more likely to be after ICU when the diary is handed over to the patient. Therefore, if patients or others wish to continue writing in the diary after discharge from the ICU or hospital, consideration will need to be given to what potential benefits or risks there are and the support required.

Gender differences in family support were discussed and findings from study participants on reasons why male family members were less likely to write diaries were considered, which uncovered other important influencing factors including the level of literacy in the area where the study was conducted. Therefore, in addition to gendered differences in behaviours around expressing emotion in general and in particular through writing a diary, socio-demographic factors such as social deprivation and educational status, impacting on literacy levels can reduce the likelihood of male family members and female family members keeping a diary during the time in ICU.

From the findings in this study it became apparent that male family members were less likely to participate in diary writing, whereas some other family members were just too upset to write. This has implications for practice in that we need to consider how to support male family members during critical illness and those who are unable to participate in diary writing. Critical care diaries, while beneficial to some people, are not for everyone. There are groups who could potentially benefit from diaries but are unable to participate. Therefore, consideration should be given to how we can support them through the experience of critical illness. Suggestions for future research, outlined in the following section, take this into consideration as well as how

to support those who do wish to participate, for example supporting nurses in delivering this intervention.

Findings from this study are transferable beyond the study setting of an adult critical care unit in NHS Scotland. Critical care diaries are used internationally and despite variation in practice between different units and countries, this research study adds to our current knowledge and understanding. Throughout the thesis, significant detail has been provided on the research process, including the research design and methods, and the study findings. In Chapter 5, the researcher drew on existing diary literature and research where similarities were found, as well as developing a new conceptual model 'Critical Care Diaries as joint actions' to illustrate the way in which patients, family members and nurses interact with and experience diaries.

## **6.3 Suggestions for future research**

Since starting the PhD in 2011 there has been a significant increase in research conducted in this area and an ongoing interest in critical care diaries. Therefore, completion of the PhD is timely in relation to current developments in this area. Findings from the PhD study contribute to existing knowledge and our current understanding of experiences with critical care diaries however further research is required. This final section of the conclusion chapter will outline suggestions for future research with critical care diaries as well as ideas for other research relating to the findings and questions raised throughout the research process.

### **6.3.1 Nurses and critical care diaries**

There is still very little known about nurses and their experiences with diaries. Yet, as found in this study and documented in the wider literature, nurses are responsible for delivering all aspects of the diary intervention. Nurses make decisions about which patients should receive a diary and when it is appropriate to introduce this to the family. They encourage family participation, are the main healthcare professionals who write in diaries and are responsible for handing diaries over to patients recovering from critical illness. While many positive aspects have been reported by nurses, relating to the presence of diaries in the ICU, nurses can experience emotional effort from interacting with the diary. Furthermore, it was



reported that some nurses refused to participate in diary writing, even though diaries had been established in the ICU and accepted as part of the care provided. Despite these reports the researcher did not identify any nurses who did not participate and was therefore unable to explore this issue further. Nevertheless, the emotional effort experienced by nurses and the issue of not writing in the diary may potentially affect how the diary intervention is delivered and the overall quality of the diary. Therefore, further research into the impact of diaries on nurses and nursing care in the ICU is needed.

### **6.3.2 Family members and critical care diaries**

Findings from this study and other recent studies, focusing on family members and diaries, suggest that diaries can support family members in different ways with their experience of critical illness. While this is an exciting development in existing knowledge and understanding about critical care diaries, further research is required as certain groups of family members are currently underrepresented or unreached in current diary research. For example, in the ICU where the study was conducted, children were generally not allowed to visit. Despite this, children were still encouraged to contribute to the diary and other than reading reports of this practice in the diary literature, the researcher is unaware of any research focusing specifically on children's experiences with critical care diaries, whether they visit the ICU or not. Furthermore, the idea of being able to contribute remotely to diaries may potentially help family members who are not physically present in the ICU. However, at present this is unknown and therefore in addition to children's experiences with diaries this could be an area for further research with family members and diaries.

### **Developing a novel diary intervention for family members**

Findings from this study revealed that family members were actively using the diary to support their own needs in ICU, even though the diary is written to and for the patient. The researcher aims to explore this area further, having been awarded an NHS Research Scotland Early Career Researcher Fellowship (appointed in April 2017). The programme of research entitled 'Supporting family members' needs in intensive care with a novel diary intervention' aims to develop, implement and

evaluate a novel diary intervention for family members to support their needs during the time in ICU. The primary research question is:

- Can a family diary intervention in ICU support patients and family members with the experience of critical illness and recovery?

### **6.3.3 Patients and critical care diaries**

Finally, with regards to the different groups involved in diaries there is still more work to be done with patients and critical care diaries. From the literature review, it was noted that different patient groups may benefit from diaries however, as with family members, there are certain groups which have not yet been considered. The most notable of these groups are those patients admitted to ICU with a neurological diagnosis. Furthermore, as found in this study and highlighted in the implications for practice, some patients participate in diary writing after the time in ICU. Although this has been documented in the diary literature there is currently no evidence to support this or research exploring this area of diary use.

### **6.3.4 Gender and critical care diaries**

A significant finding from this study, relating to family members and diaries, was around gender and the issue of male family members being less likely to write in the diary. While gender is important, and requires further investigation, there are other issues to be considered, applying to both patients and family members. Reasons for not interacting with the diary included emotional and psychological responses to the experience of critical illness. For example, one patient avoided reading certain diary entries written by nurses and there were reports of some family members finding it too difficult and upsetting to write in the diary when they visited. Another issue raised was people's ability to read and write in the diary which, in addition to an individual's emotional or psychological status, can be associated with poor literacy skills. As levels of literacy can be influenced by socio-demographic factors such as social deprivation and educational status it would be useful to consider similar research with different groups of family members and patients and in different geographical areas to explore the relationship and impact of this further. Consideration should also be given to the development of other ways to keep an account of an ICU stay.

### **6.3.5 Supporting male family members in healthcare settings**

This study has highlighted the need to consider how we currently support male family members in healthcare settings. While the current study was conducted in an ICU setting it would be useful to explore how male family members are currently supported in other healthcare settings and what their experiences are. This recommendation has come from the finding that male family members were less likely to interact with the diary intervention.

### **6.3.6 Exploring complex interventions in healthcare**

Plummer's conceptual model of 'Stories as Joint Actions' provided a way to understand and explain experiences of critical care diaries. The researcher is interested in using and adapting this model to explore and understand other complex interventions used in healthcare. Furthermore, the approach taken in this research to exploring experiences of critical care diaries could be applied to investigating other interventions that are used to support patients and families with the experience of illness and delivered by healthcare professionals.

## **6.4 Chapter summary**

In summary, this concluding chapter has highlighted some minor limitations to the study, mainly relating to the site where the research was conducted, certain aspects of the study sample and data collection techniques. Implications for practice have been discussed, with key findings around family member involvement in diaries and gender. There is a need to provide support to those involved with diaries as writing in and reading a diary requires a certain amount of emotional effort. However, many benefits from diaries were identified and different aspects of the diaries can support patients and families with the experience of critical illness. Suggestions for future research are based on further exploration of experiences with diaries and consideration needs to be given to those groups previously not represented in diary research. Furthermore, the issue of gender and diary use requires attention, as well as how we support male family members in the healthcare setting. Finally, the research approach adopted, including the conceptual model of 'Stories as joint actions' helped to explore in depth the phenomenon of experiences with critical care

diaries, whilst uncovering indirect effects of diaries. This approach is worth considering in future research exploring healthcare interventions.



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## Appendix 1:

### Study Outline

#### **Critical Care Diaries: a qualitative study on the perspectives and experiences of patients, family members and nurses**

##### ***What is this study about?***

The overall aim of this study is to gain an understanding of the perspectives and experiences of patient's, nurse's and family member's use of critical care diaries.

No previous research has attempted to examine the use of diaries during the time the patient is in ICU as diaries are primarily aimed at helping patients during recovery. However it is during this time that diaries are created from the experiences and perspectives of family members and nursing staff before being given to the patient after discharge. It is widely accepted in the literature that the diary is used mainly by patients, nurses and family members who have been brought together through the experience of critical illness yet no research has attempted to look simultaneously at the use of critical care diaries from these multiple perspectives. This study is based on the concept that diaries are used at different times, by different people and in different ways.

##### ***Why has xxxxx ICU been selected as a research site?***

xxxxx is one of only a few sites in Scotland using critical care diaries, similar to what is described in the literature and other areas of the UK, and the only site to be using diaries of this nature on a regular basis. The study must be conducted in a unit where diaries are established so that I can identify and access potential study participants as it is within this setting that the diary is initiated, created and used before being given to the patient during their recovery.

##### ***What will happen in the study?***

The study population consists of patients recovering from critical illness, visiting family members and nursing staff involved in caring for the patient and creating the diary. These individuals will be invited to take part on the basis that they have been given the opportunity to use a diary written for the patient whilst in critical care. I plan to recruit 5 sub-groups, each containing a patient, one or two family members of that patient and a nurse who has been involved in caring for the patient. A pilot phase will determine the feasibility of this approach.

##### *Interviews*

I will interview each member of the group using a semi structured approach to discuss their experiences and views around using a diary and in relation to each other. Interviews with nurses and family members will take place whilst the patient is an inpatient. The patient will be approached for interview after discharge from critical care and will take place between three and six months post ICU discharge. Patients and family members invited to take part will need to be able to give an informed consent and engage in the interview process. Each interview will be digitally recorded and for the purposes of analysis typed out word for word. All data will be anonymised.

##### *Observation*

In order to understand Unit practice, I would like to observe interactions between nurses, patients and families in the hospital relating to diary use. Identified interactions include (i) discussions between nurses and family members about the use of a diary in ICU (ii) the time at which the diary is handed over to the patient and (iii) other instances when the diary is used e.g. at follow up visits. These observations will be recorded in the form of detailed field notes in a personal reflective diary.

In the event that a patient from a sub-group subsequently dies or their care becomes palliative it will be assumed that it is inappropriate to collect any further information from that group. However data collected up until that point will be used unless other members of the group or the patient themselves wish to withdraw their data. Further information on inclusion and exclusion criteria and withdrawal from the study will be detailed in the study protocol.

### ***What will be required of staff, patients and families in xxxxx ICU?***

#### *Study recruitment*

Nursing staff, patients and family members present in the ICU in xxxxx Hospital at the time of study recruitment who are involved in using a diary might be approached to take part in the study. I will need some support from nursing staff to inform me when it is anticipated that a diary might be started for a patient. In my clinical role working as a Critical Care Research Nurse I already have experience of approaching families of critically ill and recovering patients for research and recognise the strain that these individuals are often under during this time, especially when it comes to making a decision about research. The team caring for the patient will be asked if and when it is appropriate to approach the patient's family member(s) and the patient for potential participation. I will provide clear verbal and written information specific to their participation in the study whilst allowing time to ask questions.

Nursing staff involved in caring for these patients and families on more than two shifts when the diary has been used will also be invited to take part. If more than one nurse meets these criteria and is interested in taking part, a discussion will take place to identify one individual.

#### *Time*

Participants will be interviewed about their views on critical care diaries and how they use these diaries, which could last up to 1 hour. The timing of the interview and location will depend on each individual. It is anticipated that family members will be interviewed in the hospital either before or after visiting times, nursing staff will be interviewed during the course of their shift if it is possible to do so at an appropriate location close to the clinical area and patients will be interviewed at a location suitable to their individual preferences and abilities, which may involve visiting them in their own home.

### ***Potential benefits of this research***

The need to involve and engage service users in shaping the services we provide is fundamental in ensuring that we continue to promote and deliver care of the highest standard but more importantly, care that is relevant and meets the needs of those who require it. This study will offer participants the opportunity to discuss their views and experiences on using critical care diaries thus providing a unique, rich and important source of information. The results can be used on a local and national level to inform practice by providing insight into one aspect of the follow up service at xxxxx ICU from the experiences and perspectives of service users and providers throughout the critical care journey, whilst also adding to the existing knowledge on how diaries are used by these individuals.

## Appendix 2:

### Letter for nursing staff



Nursing Studies  
SCHOOL of HEALTH IN SOCIAL SCIENCE

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#### Critical Care Diaries: a qualitative study

Dear Staff Member,

I am writing to inform you about a research project on critical care diaries that is happening in your critical care unit and I am looking for your support. The project has been approved by an NHS Research Ethics Committee, NHS xxxxx Research and Development and has support from senior members of staff in your unit.

The project aims to explore the experiences and perspectives of patients, family members and nursing staff with critical care diaries. There are two key parts to this study that you may be involved in as a nurse working in the unit. These are qualitative interviews which will be conducted with a small number of patients, family members and nursing staff and observations of nursing staff. Observations will be focused around nursing activities and interactions relating to diaries as well as general discussion with nursing staff about diaries while I am visiting the unit. I will make some notes at the time of observing to help me remember what activity I was observing and what happened.

Participation in the study is voluntary and you do not have to take part if you do not wish to. However I would appreciate it if you can take a little time to read through the attached Nursing Information Sheet on observation to consider if you are willing to participate in the observation part of the study or not. I will be approaching nursing staff when I am in the unit to ask if I can observe during the course of the study and it would be helpful if you already have some insight into this. I will also approach you individually if you are eligible to take part in a separate interview.

If you would like further information about the study or have any questions at any point during the study please feel free to contact me via my email address [corrienne.mcculloch@nhs.net](mailto:corrienne.mcculloch@nhs.net) or approach me when I am visiting the unit.

For the purpose of the study I am a nurse researcher and will therefore not be involved in providing direct patient care or clinical decision making. However I appreciate that it might be a bit strange initially having a 'nurse' from another critical care unit present but I would like to remind you that you are the experts. I am here to learn about the work you do with critical care diaries, having never

Critical care diaries: a qualitative study. Letter to nursing staff. Version 3 24Oct2012. Corrienne McCulloch

used these in practice, and look forward to meeting you. I hope that through this partnership we can generate knowledge that is relevant to practice and the experiences of those facing the critical illness journey.

Yours faithfully,

Corrienne McCulloch

## Appendix 3:

### Information sheet for nurses – observing use of diaries



THE UNIVERSITY of EDINBURGH

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INFORMATION SHEET FOR NURSES – OBSERVING USE OF DIARIES

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Version 4

Date: 11<sup>th</sup> December 2012

**Study title - Critical care diaries: a qualitative study on the perspectives and experiences of patients, family members and nurses.**

You are invited to take part in a research study. Before you decide to take part, it is important you understand why the research is being done and what it will involve. Please read the following information carefully. If there is anything that is not clear please do not hesitate to contact me.

**Background**

Critical care diaries are currently being used in intensive care units (ICUs) across Europe and the UK to help patients and their families come to terms with what has happened during the time spent in the ICU. Diaries are created from the experiences and perspectives of family members and nursing staff in the ICU before being given to the patient after discharge. Patients, family members and nurses are brought together through the experience of critical illness and can be involved in creating and using the diary at different times throughout this journey. However, although this is acknowledged in the literature, no research has attempted to look at the multiple perspectives and experiences of these groups with diaries and the benefit or impact that a diary may have within this context. Diaries are implemented and managed by nursing staff and considered to be a nursing intervention yet the views and experiences of nurses are the ones we know least about. We also need more information on the experiences and views of patients and family members with critical care diaries.

**Aims**

As part of my PhD, I am conducting a study exploring the perspectives and experiences of patients, family members and nurses with critical care diaries during and after a stay in the ICU. I wish to gain an insight into the experiences people have with critical care diaries, including what people think about them and how they are currently used in practice. I have chosen to look at nurses, family members and patients as these are the three main groups involved in writing and reading the diary. I am also interested in the context in which the diary is created and used in ICU and will therefore spend time observing in the practice setting while there are diary related activities or interactions with others in relation to the diaries.

**What it will involve for you?**

If you decide to take part you will be observed by the researcher for a short period when undertaking care related to use of a diary and be involved in informal discussion about critical care diaries.



***Do I have to take part?***

No, taking part is completely voluntary and you are not obliged to take part.

***What will happen if I want to take part?***

If you decide to allow me to observe you during the course of the study you will be asked to complete a consent form. This will be given to you prior to the first observation being carried out. I will make some informal notes while I am observing any diary related activity or interaction you are involved in and I may ask you to explain some details of what happened after the event to ensure I understand what was going on. I may observe you on more than one occasion but will make sure that you and any others involved are happy for me to be present before any observation. In addition to your consent, anyone who is present during an activity or interaction relating to diaries will be informed about the plan to observe this and will be asked to complete a written consent form prior to the observation taking place.

All information gathered during observations will be kept confidential; you will be allocated a code number to ensure you remain anonymous. The notes I make will be used in my PhD thesis, presented at conferences and in articles published in journals and will be kept anonymous at all times. The data gathered will be stored securely on a password protected university computer. This data will be stored for up to 10 years, during which time it will be used for the purposes of this research study and may be used for further research into this area following approval from an ethics committee.

The ICU senior staff members are aware of the study and are supportive for it to go ahead. You are free to withdraw from the study at any time, without giving any reason. Likewise, before or during the course of any observation you are free to ask me to withdraw without the need to give a reason. Furthermore I will not carry out observations when others present do not wish me to be there.

***What are the possible disadvantages and risks of taking part?***

It is not thought that there are many disadvantages; however, it is possible that some people may feel uncomfortable when I am observing diary related activities or interactions in relation to diaries in the practice setting. It is therefore important that people are made aware of my presence and the study. Generic information sheets about the study are available for anyone who may be around during the course of the study and I would encourage you to inform me if you think there are any issues relating to my presence that need to be addressed.

***What are the possible benefits of taking part?***

You may or may not get a direct benefit from taking part in this study. However this part of the study will give nursing staff, who have not been invited for an interview, the opportunity to discuss their experiences and views on critical care diaries which some people may find useful. Allowing me to observe you in practice may help us to understand further how diaries are currently used in intensive care units and contribute to informing and improving the services we provide for future patients and their families experiencing critical illness.

## *Will I find out the results of the study?*

It is anticipated that the results from this study will provide information on critical care diaries from a new perspective and inform practice. A summary of key findings from the study will be made available to participants. Results of this study will be fed back to the practice area and also published in professional journals.

## *What if there is a problem?*

Ethical approval has been granted from an NHS ethics committee and Management approval from NHS xxxxx to carry out this study. If you have concerns about any aspect of this study please contact me directly, using the contact details provided on the following page, and I will do my best to answer your questions. If you remain unhappy and you wish to complain formally, in the first instance please discuss this with your line manager in NHS xxxxx, you may wish to withdraw from the study or raise any issue formally with the study sponsors who can be contacted on [researchgovernance@ed.ac.uk](mailto:researchgovernance@ed.ac.uk)

## *Contact for further information*

If you would like to talk to someone who is independent from the study and experienced in critical care research then please use the alternative contact details provided below.

If you are interested in taking part in the study, have any questions or wish to discuss this part of the study further please contact me in person, by telephone or by email (details below).

<u>Researcher Contact Details:</u>	<u>Alternative Contact Details:</u>
<p>Corrienne McCulloch            PhD student in Nursing Studies/            Senior Practitioner (Clinical Research)            School of Health in Social Science            Medical School            Teviot Place            Mob: 07703468899            Email: <a href="mailto:corrienne.mcculloch@nhs.net">corrienne.mcculloch@nhs.net</a></p>	<p>Miss Jean Antonelli            Edinburgh Clinical Trials Unit            Room D36            Level 2 Outpatients Building            Western General Hospital            Crewe Road South            Edinburgh            EH4 2XU            Tel: 0131 537 2926 Mob:07917131019            Email: <a href="mailto:j.antonelli@nhs.net">j.antonelli@nhs.net</a></p>



## Appendix 4:

### Generic information sheet



#### How can you take part?

Patients and family members who meet the inclusion criteria will be given information about the study by nursing staff working in the unit. Nursing staff from the critical care unit will be approached and given information about the study by myself.

If you are interested in taking part in this study or have any further questions please feel free to contact me via email [corrienne.mcculloch@nhs.net](mailto:corrienne.mcculloch@nhs.net) or ask a member of staff for my contact number.

#### Critical Care Diaries: a qualitative study

The Intensive Care Unit at xxxxx Hospital is taking part in a study looking at the experiences and views of patients, families and nurses with critical care diaries.

#### Why is this study happening?

My name is Corrienne McCulloch and I am carrying out this study as part of my PhD in Critical Care. I am interested in finding out about patients, families and nurses experiences with diaries. I also want to



Critical care diaries: a qualitative study. Generic Information Sheet.  
Version 4 11Dec2012. Corrienne McCulloch.

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find out what people think about diaries and how they use them during and after the time in intensive care.

Diaries are currently used in this unit for some patients and their families to help them come to terms with what has happened during the time spent in intensive care. Research suggesting that diaries are helpful has often focused on clinical outcomes such as anxiety and depression. As an intensive care nurse I believe it is also important to find out what patients, family members and nursing staff think as they are the main ones involved in using diaries.

#### What will the study involve for patients, families and nurses taking part?



I will interview a small number of nursing staff, family members and patients who have been involved in using diaries. Nursing staff and family members will be interviewed during the time the patient is in hospital whilst patients will be interviewed once they have been discharged home from hospital. The interviews will give people an opportunity to tell me about their views and experiences with critical care diaries.

I will carry out some observation of nursing staff from the critical care unit whilst they go about their daily activities relating to the diaries.

Activities may involve discussions between the nurse and a member of a patient's family or a patient. I will make notes about what is happening during the time I am observing and speak to nursing staff afterwards. The focus will be on what the nurse is doing with the diary. Observing nursing staff will help me to understand better how and when diaries are used in this unit. If you are involved in an activity I plan to observe you will be informed about this. I will ask for your consent for me to observe the nurse. You do not have to agree to this and at any point during the activity you can ask me to stop observing without giving a reason.

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## **Appendix 5:**

### **Patient, Family member and Nurse Interview guides**

#### **Patient interview guide - What is the patient experience of having a diary?**

**I'd like to hear about your experiences of having a diary kept for you of the time you spent in intensive care. I will be asking some general questions to help guide our discussion. If you would like me to repeat any questions or if there are questions you do not understand or do not want to answer, please let me know.**

##### **1. Background information**

Can you tell me how you came to be in Intensive Care?

Do you remember anything from intensive care or being in hospital before coming home?

How are you getting on with things now?

##### **2. Finding out about the diary**

Can you tell me about what it was like for you to find out that the nursing staff and your family kept a diary for you when you were in intensive care?

When were you first aware of a diary being kept for you? What do you remember from that time? What were your initial thoughts and feelings? What are your thoughts and feelings now?

Do you remember when and where the diary was given to you? Who gave you the diary? What did they tell you about it?

Can you describe what this felt like? How did this make you feel?

At the time did you want (to receive) your diary? Can you tell me some of the reasons why you wanted or did not want your diary at that time? How do you feel about having the diary now?

##### **3. What patients do with their diaries after intensive care**

Can you tell me about how you have used / use the diary?

What did you do with the diary when you were given it? What about when you got home?

Have you read what is written in the diary? What things have you read?

Can you tell me about what it is like reading the diary? How did you feel about reading the diary for the first time? When you read the diary was it what you expected, if not can you tell me what you had expected?

What is it like to read entries from people you maybe don't know or remember (nurses)?

What would you say the main things were that influenced your decision to read the diary or not? What were your reasons for deciding to use the diary?

How do you feel when you read the diary now? What things are particularly helpful? Have you ever read anything that upset you? If so, why did it upset you?

What is it like to read about things you don't remember happening?

When was the last time you read the diary? Was there a reason for wanting to read the diary at this time or any other time?

What about your family, do they use the diary? How have other people in the family used it? What about any male relatives?

#### **4. Having the diary after intensive care**

Does the diary help you in anyway? Can you explain or describe a bit more about how it helps you or not?

How well do you think the diary reflects what you thought actually happened? (the way that you have seen or understand things is that how it has been presented in the diary) Did you have any idea about what was going on at the time?

Do you think that the diary has any effect on the relationship you have with others or how you get on with people now that you are home e.g. family, your relative or nursing staff (at follow up visits). Can you tell me a bit more about this or give me an example?

Do you think that the diary makes a difference to the way you are able to talk about what happened? So for example if the diary wasn't there do you think that things would be different? Can you explain a bit more about this?

#### **5. Experiences with the diary**

Can you give me an example of a good day and a bad day you have had with the diary?

At the time how did this make you feel? What were you thinking? Can you explain a bit more about this?

#### **6. Thoughts on diaries**

If someone was to ask you what you think about critical care diaries, what would you say?

Any thoughts on how the nurses wrote in the diary? Any thoughts on what the nurses wrote? What kind of things would you have liked them to have written in it?

#### **7. How to improve diaries/ diary use**

Is there anything you can think of that you would want to change about your diary? What about how diaries are used in general?

Do you think doctors should write in the diary? What about other healthcare staff in the unit?

#### **8. Thoughts on use of Photographs**

Some units also use photographs of the patient and their surroundings as part of their diary. The unit you were in doesn't. Do you have any thoughts on whether that would have been helpful or not?

#### **9. Experience from the other side - P6 only**

Can you tell me a little about your experience from the other side as a relative in intensive care?

What was it like for you having a diary for your wife when she was in intensive care? What did it mean to you to be able to write in the diary or even just to have a diary there for your wife?

Did you find the diary helpful during the time your wife was in intensive care? Can you explain or describe a bit more about how it helped or not?

What were your reasons for using or not using the diary?

How did you feel about other people being able to read what you had written? How did you feel about the nurses writing to your relative?

Did you use the diary after your wife came home at all?

Does having your own diary affect you in anyway or bring back anything to you from when you were a relative in intensive care? How does this make you feel?

### **10. Close interview**

We've reached the end of our interview. Is there anything I haven't asked about that you'd like to tell me?



**Family member interview guide - What are the family member's experiences of using a diary?**

I'd like to hear about your experiences of using a diary in intensive care. I will be asking some general questions to help guide our discussion. If you would like me to repeat any questions or if there are questions you do not understand or do not want to answer, please let me know.

**1. Background information**

What's your understanding of how your relative ended up in Intensive Care?

**2. Introduction of diary**

Can you start by telling me what happened when you first heard about a diary being used for your relative in intensive care?

When were you first asked about potentially using a diary for your relative?

What were you told about diaries?

What do you remember from that time? What were your initial thoughts and feelings? What are your thoughts and feelings now?

Can you describe what it felt like? How did this make you feel?

What would you say the main things were at that time that influenced your decision to use the diary or not? What were your reasons for deciding to use the diary? How do/did you think the diary might help your relative?

When did you start using the diary?

**3. How the diary is used by family members**

Can you tell me about how you and your family use the diary?

What do/ did you do with the diary when you come/ came into visit in the intensive care unit?

What kind of things do/did you write about in the diary and why?

Do you read the diary?

How do you feel when you read the diary? What things are particularly helpful? Have you ever read anything that upset you? If so, why did it upset you?

How do other members of the family use the diary?

Do you talk amongst yourselves about whether/what you're going to write in the diary?

Any thoughts on how the nurses write in the diary? Any thoughts on what the nurses write in it? What kind of things would you like them to write in it?

**4. Using the diary in intensive care**

Can you tell me about what it is like using the diary? (Writing in it / reading it during the time in intensive care)

What does this mean to you? What does it mean to you to be able to write in the diary or read it?

How does this make you feel?

Does the diary help you in anyway? Can you explain/ describe a bit more about how it helps you or not?

How well do you think the diary reflects your perception of what actually happened? (the way that you have seen or understand things is that how it has been presented in the diary)

Do you think that the diary has any effect on the relationship you have with others or how you get on with people e.g. family, your relative or nursing staff. Can you tell me a bit more about this or give me an example?

Do you think that the diary influences communication (giving and receiving of information) in the unit? So for example if the diary wasn't there do you think that communication would be different? Can you explain a bit more about this?

### **5. Experiences with the diary**

Can you give me an example of a good experience and a bad experience you have had with the diary?

At the time how did this make you feel? What were you thinking? Can you explain a bit more about this?

### **6. Thoughts on diaries**

If someone was to ask you what you think about critical care diaries, what would you say?

### **7. How to improve diaries/ diary use**

Is there anything you can think of that you would want to change about diaries and how they're used? Other people have said, for example, that.....

### **8. Thoughts on use of Photographs**

Some units also use photographs of the patient and their surroundings as part of their diary. This unit doesn't. Do you have any thoughts on whether that would be helpful or not?

### **9. Close interview**

We've reached the end of our interview. Is there anything I haven't asked about that you'd like to tell me?

## **Nurse interview guide - What are nurses experiences of using a diary?**

**I'd like to hear about your experiences of using a diary. I will be asking some general questions to help guide our discussion. If you would like me to repeat any questions or if there are questions you do not understand or do not want to answer, please let me know.**

### **1. Introduction of diaries in the unit**

When did you first hear about critical care diaries being used in this unit?

What do you remember about that time? What were your initial thoughts?

What would you say the main things were that have influenced your decision around using diaries?

### **2. How diaries are used in intensive care**

Can you tell me about how diaries are used in the adult critical care unit?

What would you say the main reasons were for starting a diary? Are there any circumstances where you wouldn't start or use a diary?

What information do you give to family members and patients about the diary when they are in the unit?

Can you tell me what it's like to approach a family member for the first time to introduce the diary? How does this make you feel?

What about approaching a patient?

### **3. How a diary is used by nurses in intensive care**

Can you explain to me how you use the diary in intensive care?

What do you do with the diary?

What kind of things do you write about in the diary? How do you decide what to write?

What do you think about when you are writing?

What kind of things do you read about in the diary?

Is there anything you do with the diary that other nurses in the unit don't?

### **4. Keeping a diary for patients and their families**

Can you tell me what it is like keeping a diary for your patient and their family?

What does this mean to you? What does it mean to you to be able to write in the diary for your patient?

How does it feel to be writing to someone you don't know?

What is it like reading entries that other people have written? How does this make you feel?

How do you feel about other people reading what you have written?

Do you think families get anything from reading and writing in the diary?

What about patient xxx and their family can you tell me how you think the diary worked for them? Were they involved in using the diary? What kind of things did that family write? Was this typical of how other families use diaries in the unit?

### **5. Looking after patients who have diaries kept for them**

Does the diary help in anyway or not when you are looking after a patient? (E.g. caring for the patient and their family, making decisions?) Can you explain or describe a bit more about how the diary helps you or doesn't help you?

Does the information you read in the diary make any difference to the way you care for patients? Can you give me an example?

Do you think the diary makes any difference to how you think about the patient (as a person)?

Does the diary have any effect on how you interact with the patient?

What about caring for the family?

### **6. Relating to other people when a diary is being used**

Can you tell me about how the diary helps you or not to relate to other people?

Do you think that the diary has any effect on the relationships you have with others or how you get on with people e.g. patient, family or other nursing staff. Can you tell me a bit more about this and give me an example?

How is communication at the bed space when a diary is being used (giving and receiving of information)? Do you think that diaries influence communication in the unit? So for example if the diary wasn't there do you think communication would be different? Can you explain a little more about this? Can you give me an example?

### **7. Experiences with diaries**

Can you tell me about some of the difficulties and challenges you have had with using diaries?

What about things that have worked well with diaries?

At the time how did this make you feel? What were you thinking? Can you explain a bit more about this?

### **8. Thoughts on diaries**

If someone was to say to you 'what do you think about critical care diaries', what would you tell them?

### **9. How to improve diaries/ diary use**

As an intensive care nurse and having had some involvement with diaries in this area, is there anything you can think of that you would want to change about them and how they are used?

**10. Thoughts on use of photographs**

You may or may not be aware but other units using diaries also take photographs to put in the diary, these can be of the patient and their surroundings, do you have any thoughts on this?

**11. Close interview**

We've reached the end of our interview. Is there anything I haven't asked about that you'd like to tell me?

## Appendix 6:

### Observation data collection form

Observation ID:

Date:

Location:

Starting time:

Finishing time:

Activity:

Participants present:

.....  
.....

- Physical actions of the nurse e.g. facial expressions, gestures
- What information does the nurse give about the diary and how is this delivered e.g. tone of voice, words used?
- How is the diary as an object being used/ presented in the activity (physical/ symbolic)?



## Appendix 7:

### OBSERVATION LOG

Observation number	Date	Location	Activity	Participants present
O-01				



**QUALITATIVE INTERVIEW STUDY RECRUITMENT LOG**

Study ID	Initials	Year of birth	Date of consent	Date of Interview	Date 3 months post ICU discharge
FM1					
N1					
P1					

## Appendix 8:

### Preparing quotes for use in thesis

#### Insertion of commas and full stops

The interview transcripts had been transcribed verbatim by the researcher and lacked any sentence structure. Therefore once quotes were selected the researcher reviewed and inserted commas and full stops to ensure the quotes made sense when reading them.

Quotes were extracted from the researcher's project file on NVIVO. This is where all the interview transcripts had been uploaded for the purpose of coding. Quotes were found by manually searching through the relevant nodes grouped under each theme and sub theme. A text search was used for instances where the researcher could remember a certain word a participant used but could not find the actual passage.

#### Replacing words

Some of the reasons for replacing words:

- it was difficult to read and understand the quote
- some words were not used very often or were specific to an individual participant's accent rather than the common dialect or scots language used
- the word had more than one meaning which could be confusing to the reader so it was either not used at all or used for one meaning only e.g. ae, aw
- there was more than one word or way of saying the word e.g. maself and masell

a'd – I'd

ae – of, to (abbreviation of tae)

aff - off

aen – own

ah - have

anymare - anymore

aw – oh, all

awright – alright

fur – for

gonnae – gonna, going to

hink – think

her/ his sell – herself / his self

hoor - hour

hud, hudn't, hid – had, had not

huving – having

jist - just

kinah, kinnah – kinda

maself, masell – myself

mibae – maybe

naebdae - nobody

oan – on

pit - put

saed - said

so's – so, so that

somedae – somebody  
sorta – sort of  
thit - that  
thoaght – thought  
thum - them  
wae, wi – with  
wan - one  
wur - were  
whit - what  
wis – was  
wisnae – wasnae, was not  
yae - you  
yer – your, you are  
you's – you, directed to a group of people

Some words ending in ing were pronounced without the g. For completeness and understanding the g was added. For example talkin = talking, startin = starting, feelin = feeling.

Pronunciation of some words different, vowels or sounds changed. E.g. thit = that, wur = were, yae = you, mibae = maybe

### **Keeping words/ phrases**

#### **Glossary of words**

about - about  
ah – I  
am – I'm  
an – and  
av – I've  
aw – all  
aye – yes  
blethering -  
cannae – can not  
cause – because  
couldnae - could not  
couried in – tucked in, cosy  
dae – do  
didnae – did not  
dinae – do not  
doesnae – does not  
doon – down  
dunno – do not know  
d'you – do you  
fae - from  
fricken – substitute for the F word  
gonna – going to  
grandkids – grandchildren  
hen – term of endearment usually addressed to a female  
hinging – hanging  
intae - into  
kin - can

ma – my  
mind – remember  
nah - no  
noo - now  
oot – out  
oor – our  
ratty – feeling irritable  
tae – to  
telt – told  
wanna – want to  
wasnae – was not  
werenae – were not  
wouldnae – would not  
wee – little  
woulda – would have  
windae – window

### Example

Quote taken from interview transcript:

...it was great because it felt like you were **gettin** a lot **aff** yer chest you know what ah mean when ma dad no **bein** here **anymare** an then ma mum **lyin** here ah don't have any parents, av no got a partner an ah was like...ah **thoaght** ah was gonna burst cause you know you've got aw that inside **yae**...an the first night ah wrote in the diary ah **hink** ah wrote about two pages (laughs)...an see when ah left here ah felt like 'that's good' you feel like **yer** getting it oot when you write it doon d'you know what ah mean av always done that if av got a problem ah don't want anybody to know ah right it doon and burn it...but **huving** that there ah **thoaght** was fabulous cause it just...

**Interviewer:** uh hu

**Katrina:** it felt like you **wur** **talkin** tae somebody...

Quote as it now appears in findings chapter:

*It was great because it felt like you were getting a lot off your chest. You know what ah mean with ma dad no being here anymore an then ma mum lying here. Ah don't have any parents, av no got a partner and ah was like, ah thought ah was gonna burst. Cause you know you've got aw that inside you. The first night ah wrote in the diary ah think ah wrote about two pages (laughs) an see when ah left here ah felt like 'that's good'. You feel like you're getting it oot when you write it doon, d'you know what ah mean. Av always done that if av got a problem ah don't want anybody to know, ah write it doon and burn it. But having that there ah thought was fabulous cause it just...it felt like you were talking tae somebody. (Katrina FM4)*